

Racial differences in symptom management experiences during breast cancer treatment

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Abstract

Purpose Racial disparities in cancer treatment-related symptom burden are well documented and linked to worse treatment outcomes. Yet, little is known about racial differences in patients' treatment-related symptom management experiences. Such understanding can help identify modifiable drivers of symptom burden inequities. As part of the Cancer Health Accountability for Managing Pain and Symptoms (CHAMPS) study, we examined racial differences in symptom management experiences among Black and White breast cancer survivors (BCS).

Methods We conducted six focus groups ($n = 3$ Black BCS groups; $n = 3$ White BCS groups) with 22 stages I–IV BCS at two cancer centers. Focus groups were audio-recorded and transcribed verbatim. Based on key community-based participatory research principles, our community/academic/medical partner team facilitated focus groups and conducted qualitative analyses.

Results All BCS described positive symptom management experiences, including clinician attentiveness to symptom concerns and clinician recommendations for pre-emptively managing symptoms. Black BCS commonly reported having to advocate for themselves to get information about treatment-related symptoms, and indicated dissatisfaction regarding clinicians' failure to disclose potential treatment-related symptoms or provide medications to address symptoms. White BCS often described dissatisfaction regarding inadequate information on symptom origins and clinicians' failure to offer reassurance.

Conclusions This study elucidates opportunities for future research aimed at improving equity for cancer treatment-related symptom management. For Black women, warnings about anticipated symptoms and treatment for ongoing symptoms were particular areas of concern. Routine symptom assessment for all women, as well as clinicians' management of

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symptoms for racially diverse cancer patients, need to be more thoroughly studied and addressed.

Keywords Breast cancer · Blacks/African-Americans · Symptom management · Patient-provider communication

Background

Treatment-related symptoms and side effects (e.g., pain, nausea/vomiting, fatigue, depression) are a major concern for cancer patients [1–4]. Symptoms can occur during and after treatment completion and can negatively affect cancer patients' health-related quality of life if suitable symptom management and supportive care services are not provided [5–7]. Furthermore, poorly managed symptoms can result in cancer treatment delays and non-adherence, with negative implications for survival [8, 9].

Although treatment-related symptoms are commonly reported by cancer patients, there are racial differences in treatment-related symptom burden and receipt of symptom management and supportive care services [10–13]. Compared with White women, Black women are more likely to report pain, skin irritations, and decrements in physical functioning during breast cancer treatment [2, 14–16]. Black breast cancer patients also report more unmet symptom management needs than their White counterparts [17].

While there is extensive literature documenting racial differences in health-care experiences among cancer and non-cancer patients (e.g., provider communication, provider bias) [18–20], less is known about racial differences in treatment-related symptom management experiences among cancer patients. Understanding racial differences in patient perspectives on symptom management is important, as inequities in symptom management and burden may contribute to disparities in treatment completion and cancer care outcomes [1, 9, 21, 22]. Such understanding can inform future interventions aimed at improving equity in symptom management and other supportive cancer care services.

Cancer Health Accountability for Managing Pain and Symptoms (CHAMPS) is a National Cancer Institute (NCI)-funded, community-based participatory research (CBPR) study exploring racial differences in treatment-related symptoms, symptom management, and treatment completion among stages I–IV Black and White breast cancer survivors (BCS). As a supplemental project to the NCI funded, Accountability for Cancer Care through Undoing Racism and Equity (ACCURE) intervention study, CHAMPS is grounded in principles of system-level *transparency* (e.g., monitoring overall and race-specific clinical data) and *accountability* (e.g., “audit and feedback” to clinicians on clinical performance) [23] for promoting racial equity in cancer care. Leveraging a 14-year community-medical-academic

partnership, the CHAMPS research team includes partners from the University of North Carolina at Chapel Hill (UNC-CH), Greensboro Health Disparities Collaborative (GHDC), University of Pittsburgh Medical Center-Hillman Cancer Center (UPMC-HCC), Cone Health Cancer Center (CHCC), and BCS from Sisters Network Greensboro (SNG). This paper summarizes findings from CHAMPS focus groups examining racial differences in symptom management experiences during breast cancer treatment.

Methods

Participant recruitment

Lists of eligible participants were obtained from CHCC and UPMC-HCC cancer registries and approved by oncologists at both cancer centers prior to recruitment. Eligibility criteria included: (1) Black or White race; (2) aged ≥ 18 years; (3) diagnosed with stages I–IV breast cancer; (4) received primary treatment at CHCC or UPMC-CC; and (5) completed primary treatment within the past 24 months. Eligible participants were sent recruitment letters with telephone follow-up by a research assistant.

Focus group interview procedures and data collection

Six 90-min, race-specific focus group interviews were conducted with 22 stages I–IV BCS at CHCC and UPMC-CC during November 2015 to April 2016. No more than five participants were assigned to each focus group to ensure equitable involvement from all participants [24, 25]. A racially diverse team of community and academic partners were trained to serve as moderators and note takers. Moderators obtained informed consent from all individual participants included in the study, reviewed study procedures with participants, and administered demographic surveys. Moderators used a focus group interview guide to elicit participants' treatment-related symptoms and symptom management experiences across five domains: physical, emotional/psychological, economic, social, and spiritual effects of breast cancer-related treatment (see Table 1). All focus groups were audio-recorded and transcribed verbatim. Participants received a \$15 gift card for study participation. The Institutional Review Boards at UNC-CH and UPMC-HCC approved this study.

Analysis

Our team of community, academic, and medical partners employed a thematic qualitative analysis approach to analyze the six transcripts [26]. Two community and two academic partners with prior qualitative analysis experience/training reviewed the semi-structured interview guide to identify

Table 1 Focus group interview guide questions

Topic	Question
Explanation and understanding of potential symptoms and side effects	When your health care provider(s) discussed treatment options with you, which of treatment-related symptoms or side effects did he/she mention? How easy (or difficult) was it for you to understand these side effects or symptoms as they were explained to you by your provider?
Impact of potential symptoms/side effects on treatment decision-making	How did your provider's sharing or not sharing information about potential treatment side effects influence your treatment choice/decision? <ul style="list-style-type: none"> • Did you decide against any treatments because of the potential side effects? <ul style="list-style-type: none"> i. Which treatments and side effects did you decide against? • Were you unaffected, or perhaps even, unaware of side effects when making a choice about your treatment course?
Treatment-related symptoms	Can you tell us about symptoms that you experienced during your cancer treatment? The symptoms could be physical, emotional or psychological, social, financial or spiritual.
Symptom management experiences	Did you seek help for any of your treatment-related symptoms? <ul style="list-style-type: none"> • Were you actually given any kind of medical treatment or help for your symptoms? What type of treatment or other type of help did you receive? From whom?
Impact of symptoms on treatment completion	Were there any symptoms that were so troubling for you that they made you want to stop treatment? <ul style="list-style-type: none"> • Did you tell any medical staff that you wanted to stop treatment? What happened? • Why did (or did not) you decide to continue?
Palliative care	Did any of your providers suggest "palliative care" as a care option for managing any of your symptoms AND what types of "palliative care" did they suggest? Were you open to receiving "palliative care" for any of your symptoms? Why or why not?
Recommendations	Based on how your symptoms were managed or addressed during treatment at your Cancer Center, if you had the power to improve the system, what would you change?

topical codes. Next, partners reviewed transcripts using a data-driven inductive approach to ascertain interpretive codes describing new concepts emerging from the focus group discussion [27, 28]. Both, topical and interpretive codes were compiled into a codebook.

Six community, academic, medical partners, including those with prior qualitative analysis experience, participated in an in-person training on the qualitative analysis technique of coding and retrieval prior to analyzing/coding transcripts. The training was led by the Principal Investigator (PI) of the CHAMPS study, an academic partner with prior experience/training in qualitative methods. Partners who completed this training were grouped into three community-academic coding pairs (i.e., one community/medical partner and one academic partner per pair), with each pair assigned to code two transcripts manually (on paper) using the codebook. Pairs coded assigned transcripts and identified potential themes overall and by race. To further ensure inter-coder reliability, the CHAMPS Research Assistant (RA) coded all transcripts separately and compared her coded excerpts with those generated by each coding pair, and observed consistency between both sets of coded transcripts. Next, the CHAMPS RA uploaded all transcripts into Dedoose qualitative analysis software (version 4.12), and coded transcripts electronically using excerpts identified by each coding pair. The CHAMPS PI and RA reviewed the

Dedoose-generated code report to identify overall and race-specific themes across all transcripts and summarized themes into a summary report that was shared with partners. A follow-up meeting was held with partners to discuss key findings in the report. Several themes emerged during the analysis process; however, the results reported in this paper focus on themes related to symptom management experiences during treatment.

Results

Participant characteristics

The study sample ($N = 22$) included 10 Black and 12 White BCS (Table 2). Mean age for Black and White participants was 66 and 65 years, respectively. Most Black participants (6 out of 10) had a stage I or II diagnosis, while the majority of White participants (9 out of 12) had a stage II or III diagnosis. Participants had a mean time since diagnosis of 31 months. Most participants (20 out of 22) were covered by Medicare and/or private insurance. Cancer treatments received included surgery, chemotherapy, radiation, and hormonal therapy. Participants reported a range of treatment-related symptoms and side effects (e.g., hair loss, pain, nausea, anxiety, depression/sadness; Table 3).

Table 2 Focus group participant characteristics ($N = 22$)

	Black	White
Number of participants (N)	10	12
Mean age (years (SD))	66 (10.9)	65 (13.1)
Time since diagnosis, months (SD)	31 (5.4)	31 (8.6)
Stage (n)*		
Stage 1	3	3
Stage 2	3	4
Stage 3	2	5
Stage 4	1	0
Cancer treatments received		
Surgery	8	12
Chemotherapy	4	6
Radiation	8	12
Hormonal therapy	5	9
Other	1	3
Insurance status (n)		
Medicaid	0	1
Medicare	2	4
Private	5	5
No insurance	1	0
Multiple (Medicare + Medicaid or private)	2	2

*Note: Numbers may not add up to total N due to missing data

Overview of key themes

Five themes reflecting participants' symptom management experiences emerged from the focus group analysis (Table 4). Below, we summarize *overall patterns* among both, Black and White BCS, as well as *race-specific patterns* (when applicable) in each theme.

Table 3 Commonly reported symptoms and side effects among focus group participants, by race ($N = 22$)

	Black ($n = 10$)	White ($n = 12$)
Symptom/side effect		
Hair loss	7	7
Skin toxicity/rash	5	4
Pain	5	2
Poor concentration/forgetfulness ("chemo brain")	5	4
Emotional distress (e.g., anxiety, anger, fear, sadness)	4	6
Hot flashes	3	4
Nail darkening/falling off	3	4
Diarrhea	3	1
Nausea/vomiting	2	3
Fatigue	2	4
Loss of appetite	2	2
Lymphedema	2	2
Neuropathy	2	1

Theme 1: Clinicians usually offered reassurance and validation of treatment-related symptoms

Overall patterns When asked how clinicians (e.g., doctors, nurses) responded to their treatment-related symptoms, many Black and White participants described instances when clinicians responded appropriately and empathetically. Specifically, participants reported that clinicians generally acknowledged their symptoms and encouraged or comforted them when they experienced discomfort related to treatment side effects. One participant explained,

"... I was worried and the doctors kept saying and the nurses, you know, don't worry about it, get well first."

Another participant stated, "the frozen shoulder was probably the worst experience throughout my whole experience ... but I still credit my oncologist for staying on top of it until they did get an accurate diagnosis."

Theme 2: Clinicians sometimes disregarded patient-reported symptom concerns, with Black BCS more commonly reporting instances of clinician disregard

Overall patterns Black and White participants also detailed occasions when symptoms were not treated or clinicians attributed symptoms to non-treatment causes, even when participants insisted their symptoms originated from their cancer treatment. As one participant described,

"The other thing is the doctors don't think this has anything to do [with this], but I took letrozole, and I just ... I

Table 4 Key themes and exemplary quotes related to symptom management experiences among Black and White breast cancer survivors

Themes	Quotes reflecting overall patterns among both Blacks and Whites	Quotes reflecting race-specific patterns among Blacks and Whites (where applicable)
Theme 1: Clinicians usually offered reassurance and validation of treatment-related symptoms	“... the frozen shoulder was probably the worst experience throughout my whole experience...but I still credit my oncologist for staying on top of it until they did get an accurate diagnosis.”	Whites: N/A Blacks: N/A
Theme 2: Clinicians sometimes disregarded patient-reported symptom concerns, with Black BCS more commonly reporting instances of clinician disregard	“The other thing is the doctors don't think this has anything to do [with this], but I took letrozole, and I just... I just couldn't walk. So I stopped, and I was fine. It went away. I started taking Tamoxifen, and about in August, I started having the same pain again. But the doctors don't think it's the medicine, but somehow I think the medicine is... the problem.”	Whites: N/A Blacks: “The only thing I would say is my experience with the shoulder and the radiation oncologist. I think because he said he had never really seen that before. I do not know if he thought I was just making up the pain, the real pain that I was in. But he did not really, in my mind, take it as serious, as I wanted him to know that this pain is real.”
Theme 3: Clinician communication about symptoms and symptom management was usually helpful, but information-sharing remained sub-optimal	“...a lot of the nurses gave a lot of hints... [Like] when you get your neulasta shot, take a Claritin the day before, take a Claritin the day of, take it after, get it in your stomach.... Well, I did it all. I never got sick from any neulasta.”	Whites: “I felt like I did not get good information about it being normal to be tired [from radiation]....; it was almost brushed over...” Blacks: “I said I want you to take the port out tomorrow. We will not do this. He said, ‘Why?’ And I told him all my symptoms.”
Theme 4: Patient satisfaction with symptom management varied according to responsiveness of specific members of the clinical team	“...and the neuropathy, no medication. I mean he didn't tell me about anything I could take.” “I could not have had a more wonderful experience than what I had here with my doctor and everybody else, just fabulous. I would pay more money just to come see the doctor. He's so nice to be with.”	Whites: “... a lot of the nurses gave a lot of hints... [Like] when you get your neulasta shot, take a Claritin the day before, take a Claritin the day of, take it after, get it in your stomach.... Well, I did it all. I never got sick from any neulasta.” Blacks: “That's who I would start with, my oncologist. I just felt more comfortable [with him]... I developed an infection, which they thought may have been the flu, but they wanted to make sure the infection wasn't coming from the port. Again, the oncologist did not say—‘well, you need to go to your primary.’ He was okay with making sure that I was provided for.”
Theme 5: For White BCS, dissatisfaction with symptom management stemmed from perceived clinician failure to explain symptom origins and symptom management options; but for Black BCS, dissatisfaction stemmed from perceived clinician disregard and failure to effectively address symptoms	“The doctors do not know [about this symptom]. I do not know why they do not know. They should because they are handing [treatments] out.”	Whites: “Well, nobody knows anything about lymphedema, because I asked my medical doctor about it and he said, ‘Just wear your sleeve.’ I asked the oncologist about it. I said, ‘Is not there something that can be done?’ ... ‘Just wear your sleeve.’ ... I do not know why I cannot really get any answers about it.” Blacks: “He did give me, I think it was maybe 10 or 15 pills for the [neuropathy], but it didn't do any good. I mean if I took aspirin it did better. So I lost my faith in him altogether.”

just couldn't walk. So I stopped, and I was fine. It went away. I started taking Tamoxifen, and about in August, I started having the same pain again. But the doctors don't think it's the medicine, but somehow I think the medicine is ... the problem."

Participants reported that symptoms were sometimes simply ignored by clinicians, as indicated by one participant,

"Well, like I had said earlier, when I had that trigger finger, they just—I don't even know if they wrote it down, but it was very painful initially."

Race-specific patterns While both Black and White participants reported instances of symptoms left unaddressed by clinicians, there were race-specific patterns in types of clinician disregard reported. Black participants commonly described instances where their symptom concerns were not validated (e.g., lack of concern/empathy) by their care team. For example, one Black participant explained,

"... [my doctor] did not show enough concern to make any phone calls, to have his nurse call me, to discuss what was going on.... So I was concerned with his lack of empathy."

In recounting a conversation with one of her doctors, another Black participant said,

"[My doctor] goes and talks to the oncologist and he's like, 'well, Dr. So-and-So said he could have given you'—[I told him,] 'yeah, he could have given me, but he did not take the time to question me or show any concern about the symptoms that I was having' ..."

Black participants also commonly reported instances of clinicians failing to diagnose specific symptoms (especially pain) and suggested that some clinicians' missed diagnoses were due to lack of knowledge on symptoms and symptom management. As one Black patient explained,

"The only thing I would say is my experience with the shoulder and the radiation oncologist. I think because he said he had never really seen that before I don't know if he thought I was just making up the pain, the real pain that I was in. But he didn't really, in my mind, take it as serious, as I wanted him to know that this pain is real."

Theme 3: Clinician communication about symptoms and symptom management was usually helpful, but information-sharing remained sub-optimal

Overall patterns Several participants reported that clinicians shared helpful information on treatment-related symptoms during the initial overview of their cancer treatment or in response to their questions regarding treatment-related symptoms. During actual treatment, participants reported getting helpful tips on symptom management from their oncology care team. One participant stated:

"... a lot of the nurses gave a lot of hints ... [Like] when you get your neulasta shot, take a Claritin the day before, take a Claritin the day of, take it after, get it in your stomach ... Well, I did it all. I never got sick from any neulasta."

Some participants also mentioned the level of detail in the symptom-related information provided by their cancer center. As one participant put it,

"And I mean I have binders, I have diagrams, I have everything like you know, and they explained to me the different drugs and what could happen, what could—all that kinda stuff. I have not one, like bad thing to say. I mean it was very informative."

Some participants also highlighted instances when they received incomplete or no information about their symptoms. One participant described this concern when a clinician would not appropriately follow up on her symptom concerns, stating,

"... and the neuropathy, no medication. I mean he didn't tell me about anything I could take."

Race-specific patterns In terms of race-specific patterns, White BCS commonly reported lack of complete information concerning their symptoms, as one White patient noted,

"I felt like I did not get good information about it being normal to be tired [from radiation]..., it was almost brushed over ..."

Black participants often described having to advocate for themselves to get clinicians to explain, diagnose, and manage their treatment-related symptoms. One Black BCS reported speaking to her surgeon,

“I said I want you to take the port out tomorrow. We will not do this. He said, ‘Why?’ And I told him all my symptoms.”

For this patient, poor communication regarding symptoms and management options and constant need for self-advocacy led to a decision to stop treatment without consulting her clinical care team.

Theme 4: Patient satisfaction with symptom management varied according to responsiveness of specific members of the clinical team

Overall patterns When asked directly about satisfaction with symptom management, many Black and White participants initially reported that they were satisfied with their providers’ attentiveness and/or response to their treatment-related symptoms. As one participant described,

“I couldn’t have had a more wonderful experience than what I had here with my doctor and everybody else, just fabulous. I would pay more money just to come see the doctor. He’s so nice to be with.”

Race-specific patterns There were also racial differences in participants’ reported satisfaction with different types of providers. White participants commonly reported satisfaction with nurses because they answered questions, provided supportive care medications, or were “helpful in giving hints” to avoid or address symptoms before or after treatment. One White participant noted, “the nurses know what kind of creams to use.” White participants also expressed satisfaction with doctors, in general, because doctors were attentive and addressed their symptoms. As one White participant expressed,

“Dr. [name] is just wonderful. He is. Everyone should have him because he’s so attentive.”

Another White participant stated, “My doctors were fine. They explained everything over and above.”

Black participants, however, reported satisfaction specifically with their surgeons, who immediately provided them with medication to address symptoms, and their oncologists, who provided a symptom diagnosis. As one Black participant expressed,

“My surgeon is an angel. You sent me an angel to hook up my medication.”

Another Black participant spoke of her oncologist noting,

“That’s who I would start with, my oncologist. I just felt more comfortable [with him] ... I developed an infection, which they thought may have been the flu, but they wanted to make sure the infection wasn’t coming from the port. Again, the oncologist didn’t say—‘well, you need to go to your primary.’ He was okay with making sure that I was provided for.”

Theme 5: For White BCS, dissatisfaction with symptom management stemmed from perceived clinician failure to explain symptom origins and symptom management options; but for Black BCS, dissatisfaction stemmed from perceived clinician disregard and failure to effectively address symptoms

Overall patterns Despite initially indicating satisfaction with their symptom management, further probing revealed that both Black and White participants also experienced dissatisfaction with clinicians’ knowledge of and responsiveness to symptoms. For example, one participant noted,

“The doctors don’t know [about this symptom]. I don’t know why they don’t know. They should because they’re handing [treatments] out.”

Race-specific patterns White participants commonly reported disappointment regarding clinicians’ failure to diagnose a symptom, fully explain the origins of their symptoms, or acknowledge and provide reassurance about addressing symptoms. As one White participant described,

“Well, nobody knows anything about lymphedema, because I asked my medical doctor about it and he said, ‘Just wear your sleeve.’ I asked the oncologist about it. I said, ‘Isn’t there something that can be done?’ ... ‘Just wear your sleeve.’ ... I don’t know why I can’t really get any answers about it.”

Some Black participants reported dissatisfaction regarding clinicians’ failure to properly address their pain or provide medication for symptoms. In explaining this failure, one participant said,

“He did give me, I think it was maybe 10 or 15 pills for the [neuropathy], but it didn’t do any good. I mean if I took aspirin it did better. So I lost my faith in him altogether.”

Other Black participants reported dissatisfaction and mistrust stemming from perceived clinician disregard,

belittlement, or clinician failure to discuss potential treatment-related symptoms. One Black participant explained,

“I felt like he was treating me in a childlike manner. He was only giving me little doses of what he thought I could handle ... and I dislike for people to underestimate my intelligence. So he didn’t win me over as a fan.”

Another Black participant stated,

“And then my ... oncologist, when he told me I wasn’t gonna have any symptoms, my hair comes out, I’m nauseous, I’ve got diarrhea, so I lost, like, a lot of faith in him because he did not tell me the straight up truth.”

A few Black participants also expressed a feeling of differential treatment from clinicians based on their race or insurance status as indicated by a participant sharing,

“The one doctor. I don’t know whether it was me or whether it was my race or whatever, but his body language said I do not want to be bothered with you ...”

Discussion

Managing treatment-related symptoms is critical to delivering high-quality cancer care and optimizing cancer care outcomes [1, 5–7, 21, 22]. Given the significance of symptom management across the cancer care continuum and well-documented racial/ethnic disparities in cancer-related symptom burden [11–13, 17, 29–33], it is important to delineate race-specific patterns in symptom management experiences that might contribute to symptom-related disparities. In this study, we explored symptom management experiences among Black and White BCS from two cancer centers. We found that both Black and White participants reported positive symptom management experiences, including clinician reassurance and attentiveness to symptom concerns, patient-clinician communication regarding symptoms to expect during treatment, and treatment team members sharing tips and recommendations for pre-emptively managing symptoms. At the same time, negative symptom management experiences varied by racial group. Black participants commonly reported negative symptom management experiences and dissatisfaction with clinicians’ dismissive attitudes, and failure to explain potential treatment-related side effects, or offer adequate remedies. Whereas, White participants often described dissatisfaction with inadequate information sharing regarding symptoms and clinician failure to offer reassurance for symptom management. These findings elucidate potential targets for future

research aimed at understanding and addressing inequities in cancer treatment-related symptom management.

Findings revealing inadequacy of patient-clinician communication on treatment-related symptoms and symptom management options are consistent with findings from other recent work [34], and highlight the potential need for additional clinician training. Such training could focus on identifying and addressing physical (e.g., pain, nausea, rashes) and non-physical (e.g., emotional issues, social isolation, financial toxicity) symptoms, and the possibility of unexpected, less-common symptoms. In addition, supplemental pamphlets or other patient education materials can be distributed and reviewed with patients at each clinic visit [35, 36]. Such proactive actions can potentially lead to more equitable and timely delivery of patient-centered, supportive cancer care services, as clinicians and patients become more activated and engaged in managing the wide-ranging psychosocial effects of cancer and its treatment [37].

Multiple Black participants described experiences where symptoms were disregarded or unaddressed by clinicians. Previous studies have documented racial differences in clinician symptom assessments, with clinicians more likely to underestimate the symptom burden of racially diverse cancer patients [38]. Such disparities may lead to inequities in the delivery of symptom management services and compromise patient care outcomes. Emerging evidence suggests that routinizing symptom assessment and documentation through the integration of patient-reported outcome measures [39–41] into routine oncology practice may mitigate inequities in symptom monitoring and management by tracking patients’ symptom trajectories (i.e., improving *transparency*) and alerting clinicians to patients with worsening symptoms (i.e., improving *accountability*). Such routinized systems for symptom monitoring could also be leveraged for race-specific symptom monitoring, where oncology practices could monitor their progress in achieving racial equity in symptom management among their patient population and identify areas for improvement.

Moreover, our findings highlight the potential benefit and promise of integrating palliative/supportive cancer care services into routine oncology care. Approaches for integrating such services into routine care include specialty palliative care provided by palliative medicine specialists and primary palliative care provided directly to patients by oncologists and oncology nurses [35, 36, 42]. Because palliative medicine specialists are well versed in the array of symptoms experienced by cancer patients, specialty palliative care teams are well positioned to address patient questions regarding potential and current symptoms and offer recommendations for alleviating symptoms. However, there is currently a shortage in the supply of palliative medicine specialists relative to the potential demand among cancer patients, making equitable access and coordination a challenge [42]. As care fragmentation is more commonly reported among

patients of color and linked to lower care utilization and worse care outcomes [43–45], integrating palliative/supportive cancer care services into routine care through primary palliative care may help promote equity in the coordination and delivery symptom management of symptom management services [35].

Strengths and limitations

Limitations of this study include our focus on Black and White BCS; thus, our findings may not apply to other racial or ethnic groups. Recall bias may have also been an issue, as participants were BCS within 24 months of completing primary treatment; however, we intentionally selected survivors, rather than patients in active treatment, to ascertain the range of symptom management experienced across the cancer care continuum. Strengths include our CBPR approach, which leveraged valuable insights from community, academic, and medical partners. To maximize variation in perspectives, we recruited Black and White BCS from two cancer centers (one academic and one community-based), which enhances reproducibility of our findings. We also conducted race-stratified focus groups, which facilitated transparent discussions regarding perceived racial differences in symptom-related treatment experiences.

Conclusions

To our knowledge, this is the first CBPR study to examine racial differences in symptom management experiences during breast cancer treatment. Our findings point to potential targets for future research inquiry, including: routine symptom assessments with race-specific symptom monitoring, integration of palliative/supportive care services into routine oncology care, and improved clinician communication regarding potential symptoms and symptom management options. Additionally, future research should explore barriers to use of palliative/supportive care services among racially diverse cancer patients.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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