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# Racial disparity in breast cancer survivorship: themes from a series of four national healthcare provider live virtual forums

**Jill M. Binkley**[1,2] · **Sheryl Gabram**[2,3] · **Janae Finley**[1,2] · **Dawnovise Fowler**[4] · **Lisa VanHoose**[2,5,6] · **Lauren E. McCullough**[7]

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## Abstract

**Purpose** Significant disparity exists in the diagnosis, treatment, and survivorship outcomes among Black breast cancer (BC) survivors. Black BC survivors have more significant survivorship issues and a greater burden of illness than White counterparts. Barriers to rehabilitation exist for all BC survivors but are magnified in Black BC survivors. The purpose of this qualitative research was to document patient, clinician, and researchers' perceptions surrounding contributing factors, lived experiences, and potential solutions to racial disparity in BC survivorship.

**Methods** A narrative approach was utilized to identify themes from a series of four virtual healthcare provider forums that explored lived personal and professional experiences, issues, and potential solutions surrounding racial disparity in BC survivorship. Forums included perspectives of patients, healthcare providers, researchers, and stakeholders in the BC field. An independent thematic analysis was performed by the investigators, all of whom have emic perspectives with respect to race and/or BC.

**Results** Three main themes were identified related to racial disparity in BC survivorship: (1) societal and cultural contributing factors, (2) contribution of healthcare providers and systems, and (3) models of care and research considerations.

**Conclusions** The findings provide compelling documentation of lived personal and professional experiences of racial disparity in BC survivorship. Potential solutions exist and must be enacted immediately to ensure equitable survivorship outcomes for Black individuals following a BC diagnosis.

**Implications for Cancer Survivors** Increased awareness related to racial disparity in BC survivorship among survivors, healthcare providers, and researchers will contribute to health equity and improved outcomes for Black individuals.

**Keywords** Racial disparity · Health equity · Breast cancer survivorship · Breast cancer outcomes · Breast cancer rehabilitation · Oncology physical therapy · Navigation · Prospective surveillance

## Introduction

Disparity exists in the diagnosis, treatment, and survivorship outcomes among Black breast cancer (BC) survivors [1]. BC mortality is approximately 40% higher among Black women compared with White women, with a more rapid decline over time in mortality among White women [2]. Age-adjusted mortality rate for Black women less than 40 years of age is twice that for White women [3, 4]. This is due, in part, to a greater prevalence of more aggressive and higher stage tumors at diagnosis among Black women [3]. The contribution of social factors to disparities between Black and White women are complex and multifactorial [3]. These factors include socioeconomic status, neighborhood conditions, childhood and life-long exposure to physical and psychosocial stress, and trauma. Structural, cultural,

✉ Jill M. Binkley
jill@jmbinkley.com

[1] TurningPoint Breast Cancer Rehabilitation, Atlanta, GA, USA

[2] Global Access to Breast Cancer Rehabilitation Community Partnership Initiative, Atlanta, GA, USA

[3] Georgia Center for Oncology Research and Education, Atlanta, GA, USA

[4] The Vow of Wellness, LLC, Roswell, GA, USA

[5] College of Saint Mary, Omaha, NE, USA

[6] The Ujima Center, Monroe, LA, USA

[7] Epidemiology, Rollins School of Public Health, Emory University, Atlanta, GA, USA

and individual-level racism in healthcare systems as well as implicit bias among healthcare providers are well-documented [5]. All of these issues contribute to the failure of Black women to receive timely diagnosis, optimal treatment, and contribute to poorer outcomes and elevated mortality risk in Black women [3].

Unmet physical and emotional needs in BC survivors are well-documented [6–9]. Significant adverse effects of treatment include fatigue, mobility and functional issues, pain, neuropathy, cognitive and affective dysfunction, depression, post-traumatic stress syndrome as well as sexual and body image issues. However, there is less research on survivorship coping with BC among minority women during treatment and through the course of survivorship [10–12]. Once diagnosed, Black BC survivors have more significant survivorship issues and a greater burden of illness [13–15]. Evidence supports the critical role of rehabilitation, exercise, emotional and nutritional support in maximizing quality of life during and after treatment [16]. Barriers to rehabilitation and recovery care exist for all BC survivors but are magnified in Black survivors due to systemic racism, healthcare provider bias and discrimination, lack of culturally relevant care models, and socio-economic barriers [17].

Black women encounter more physical impairments related to BC than their White counterparts, even when access to care is equal [18]. Black and low-income women are almost twice as likely as White women to have lymphedema [19]. Importantly, the negative impact on the ability to work following BC treatment is more pronounced among Black survivors [20]. Black BC survivors report more adverse effects than White survivors, including fatigue, pain, cognitive dysfunction, keloid scar formation, physical dysfunction, menopausal dysfunction, and sexual dysfunction [21].

Despite research and recommendations supporting rehabilitation and exercise during and after BC treatment, less than 20% of individuals receive this essential survivorship care [22]. National and global barriers include a dearth of specialized oncology physical therapists and community-based specialty clinics, as well as a lack of established collaboration among oncology healthcare providers and rehabilitation providers. The compounded effect of universal barriers to BC rehabilitation, more serious survivorship issues in Black women, and additional race-based barriers result in significant health inequity for Black BC survivors. In a study documenting physical and functional issues in Black women during BC treatment, greater than 30% of the women experienced significant issues, including mobility restriction, pain, and lymphedema following surgery—that would not have been addressed if not participants in the study [23]. This mirrors well-documented and historical health disparities that lead to poorer health outcomes for Black Americans.

While racial disparity in BC survivorship is increasingly reported in the literature, there has been little attention to the documentation of experiences of patients, healthcare providers, researchers, and stakeholders to shed light on causes and solutions. Illness narrative research documents the lived experiences related to a disease and events associated with medical care from a patient or family perspective, and the stories and experiences themselves become the data [24, 25]. The use of narratives from individuals with cancer has been utilized to document the cancer experience and expand patient support and care [26]. Narrative research has been responsible, in part, for lifting the cloud of stigma and silence that once shrouded a cancer diagnosis [26]. Lived experiences may include financial strain, role ineffectiveness, body image, coping strategies, and physical and emotional impact [24]. In cancer care, personal narratives afford rich insights into how encounters with cancer and the associated provision of care are experienced and nuanced through the view of survivors. Narratives of individuals with cancer necessarily reflect their material, cultural, and interpersonal contexts. As such, they may reveal as much about the norms and dominant meta-narratives of the social, cultural, and political context in which they are produced as the narrator themselves [26].

Narrative data are typically derived by asking broad, open-ended questions designed to explore people's views of reality, but may also be collected through review or documents or materials [25, 27]. Narrative approaches consider the investigator as someone who plays an integral role in constructing, guiding, and analyzing the narratives produced [25, 27]. Thematic analysis of narrative data is a common method used to identify and organize concepts emphasized in the data [24, 25]. The analysis groups concepts into themes, considering recurrence, repetition, and forcefulness of ideas in the narrative transcripts [24, 25].

Qualitative methods have been utilized to investigate ethnic and racial disparities in cancer survivors in the USA and elsewhere [28]. There is limited literature, however, on lived personal and professional experiences of racial disparity in BC survivorship. The purpose of this work was to investigate patient, clinician, and researchers' perceptions surrounding contributing factors, lived experiences, and potential solutions to racial disparity in BC survivorship against the contextual background of reported inequities. The method used was a qualitative analysis of narrations provided during a series of open forums on the topic.

## Methods

TurningPoint Breast Cancer Rehabilitation, a non-profit 501c3 organization in Atlanta, hosted a four-part virtual forum series titled "Racial Disparities in BC Survivorship" from October 2020 through September 2021. The series addressed key contributors and factors related to cancer survivorship disparities and how clinicians and researchers could improve community engagement and capacity building to reduce the disparity. The target audience was healthcare providers and stakeholders in the BC field. Average live attendance at each forum was 108 (range 62–200) with an additional average of 288 (range 150–442) online views post-event. Total live and online views for all four forums were 2093. Sixty-two percent of live attendees were healthcare providers, academics, and researchers working in the BC field, the remainder stated other. Online viewers' background is not known.

Moderators and panelists included BC patients, clinicians, researchers, and other stakeholders in the BC survivorship and racial disparity arenas. The inclusion of different stakeholders was to share perspectives, stimulate broad conversation, and allow results to be more generalizable. A total of 14 people served as panelists and moderators, four of the authors participated as a panelist and/or moderator. Table 1 provides relevant characteristics of the moderators and panelists. Topics and related open-ended questions were developed for each forum by three of the authors (JB, SG, JF) in collaboration with moderators (Table 2).

A narrative approach was utilized to document and describe themes from the forum series. The approach facilitated exploration and description of human experiences as they relate to BC survivorship and compare emerging themes with published literature. The analysis included independent review of each of the four forums by study investigators to identify themes and subthemes. The reviews were performed independently by the six authors who represent patient, clinician, and research perspectives related to BC. Investigators included 4 emic reviewers and 2 etic reviewers with respect to both race and personal BC experience. Themes were collated across authors and forums and reviewed by a single investigator (JB) and independently confirmed from the raw data by a second investigator (JF). Themes identified by more than two members of the team were included in the overall theme set. Three broad themes along with subthemes were identified. These emerged across all four forums. Themes were reviewed, refined, and approved during team meetings attended by all study investigators.

This narrative review of the publicly available forums was reviewed by Emory University Institutional Review Board and classified as not human research.

## Results

The three primary themes that emerged from the forums are summarized in Table 2 along with related panelists' quotes. The forums described lived experiences of Black BC survivors and perspectives from health care providers and researchers in the BC field. One theme was the *societal and cultural contributing factors contributing to racial disparity in BC survivorship*. Forum panelists described cultural and societal issues that contribute to the disparity in survivorship,

**Table 1** Relevant demographics of moderators and panelists (*n* = 14)

| | | Percent of group |
|---|---|---|
| Personal experience with breast cancer | | 55 |
| Experience as a breast cancer caregiver | | 22 |
| Age | 20–29 | 11 |
| | 30–39 | 34 |
| | 40–49 | 22 |
| | 50–59 | 22 |
| | 60–69 | 11 |
| | 70+ | 0 |
| Race and ethnicity | Black or African American | 66 |
| | White | 32 |
| | Hispanic or Latinx | 2 |
| Primary role related to breast cancer | Patient/breast cancer survivor | 33 |
| | Physical or occupational therapist | 11 |
| | Physician or surgeon 12 | 12 |
| | Researcher/academic 44 | 44 |
| Current, past or additional roles related to breast cancer<br>(Panelists and moderators were able to identify more than one additional role) | Patient/breast cancer survivor | 44 |
| | Physical or occupational therapist | 22 |
| | Physician or surgeon | 1 |
| | Researcher/academic | 44 |
| | Patient navigator | 11 |
| | Stakeholder or advocate | 33 |

**Table 2** Themes and related panelists' quotes

| | |
|---|---|
| **Theme 1: Societal and cultural contributing factors to racial disparity in BC survivorship**<br>• Cultural components, such as anxiety, stress, and family relationships within the Black community<br>• Health literacy disparity<br>• Racism and bias within the healthcare system<br>• Increased disparity at intersections of race, religion, nationality, culture, age, culture, sexual identity, and disability | "*Black people are not a monolith.*" (Physical Therapist (PT), Researcher. Advocate)<br>"*There is a continued cycle of misinformation within the Black community.*" (Survivor, BC PT)<br>"*Patients sacrifice family priorities to afford treatment.*" (Survivor, BC PT)<br>"*There is disparity in how education is provided, and to whom it is provided.*" (Physician)<br>"*The Black community is reluctant to complain about side effects.*" (Survivor, Advocate)<br>"*What I look like is not what I feel like…*" (Survivor, Community Advocate)<br>"*Being younger and dealing with cancer, I feel like I wasn't taken seriously, and was approached like I had a lack of knowledge.*" (BC Physician, Researcher)<br>"*Give statistical information that is real for us, [because] it impacts us quite differently.*" (Survivor)<br>"*Even as Black women we are not just our race, we need to think more carefully about the intersection of identity at which people live, and make sure we are attentive to their entire being.*" (BC Researcher) |
| **Theme 2: Healthcare providers and systems contributing factors and necessary change**<br>• Individualize care and ensure patient centered approach<br>• Display compassion and build trust<br>• Reduce power differentials<br>• Communicate transparent care options<br>• Incorporate approachability, acceptability, availability, accommodation, affordability, appropriateness when addressing equity in healthcare delivery [29]<br>• Ensure concordance between healthcare providers and patients<br>• Be aware of a strong sense of not being heard, patients may fail to communicate treatment side effects, and this may be amplified in younger BC patients<br>• Set appropriate expectations of the quality of care and advice that is offered; be aware of the stated concern of "We don't know what we don't know"<br>• Encourage healthcare providers to understand disparity and barriers to care, limiting assumptions about patients; "peel back the onion layer"<br>• Make certain that the onus is not on the patient to self-advocate for survivorship care<br>• Build community partnerships for survivorship services and research; care and programs must be culturally relevant, collaborative, lift and empower the community, sustainable "don't drop in and leave," and take time to establish meaningful relationships<br>• Recognize that financial toxicity of a cancer diagnosis is a significant barrier to quality care, including survivorship care | "*Why wouldn't they take me more seriously knowing the statistics [for Black women]*" (Physician, Researcher)<br>"*Doctors and providers should not wait till we speak up, they should be forthcoming with information, especially when they know.*" (Survivor, Community Advocate)<br>"*We don't know what we don't know- did I receive standard of care, and what is standard of care?*" (Survivor, Community Advocate)<br>"*If I had private insurance, and was at a private practice, would I be going through this, and would I have to be more proactive?*" (Survivor)<br>"*Doctors take a lot of things for granted, that you understand, and you somehow went to medical school behind their backs.*" (Survivor, Advocate)<br>"*Doctors need to say, tell me what you understand from what I told you.*" (Survivor, Advocate)<br>"*We cannot treat people equally, need to trat them equitably.*" (PT, Researcher, Advocate)<br>"*Need diversity of team and informed care to make sure that diverse groups of women feel safe.*" (Survivor, Advocate)<br>"*Make sure people [healthcare providers] are well trained to work with different populations even if team can't be racially and ethnically diverse.*" (BC Researcher)<br>"*Black women 3 times more likely to have cost related barriers.*" (PT, Researcher, Advocate)<br>"*Physical Therapists need to move away from paternalistic care and embrace shared decision making.*" (PT, Researcher)<br>"*People question if healthcare system we set up is about bettering patients or bettering someone's pocket.*" (BC Researcher)<br>"*[The] church is an area we should never leave behind, oftentimes it is where people are being mis-informed.*" (PT, Researcher) |
| **Theme 3: Models of care and research considerations to reduce racial disparity**<br>• Provide accessible patient navigation related to treatment side effects and survivorship<br>• Institute prospective surveillance model for BC for all patients<br>• Address determinants of health and the survivorship experience<br>• Attend to mental health issues and provide trauma-informed care<br>• Acknowledge that disparity in BC survivorship impacts the whole family and society in general<br>• Shift research priorities and policies to address contributors to disparity, ensure that research is community-based and change national policy related to research and funding priorities to focus on racial disparity in survivorship | "*Comprehensive follow through is what matters.*" (Survivor, Advocate)<br>"*We need to consider the 'five A's of care – approachability, acceptability, availability/accommodation, affordability and appropriateness.*" [29] (PT, Researcher)<br>"*Navigation is key to increase referral [to rehab].*" (Survivor, Surgeon, Researcher)<br>"*Need to make sure insurance companies understand the value of [navigation].*" (Physician, Researcher)<br>"*Telerehabilitation may be effective to increase access and reduce disparity.*" (Survivor, Surgeon, Researcher)<br>"*We fail our patient's because we neglect to recognize that prospective surveillance is an important cost outlay to utilize to achieve equitable care.*" (PT, Researcher)<br>"*Collaboration and partnership - community organizations have most connection with the community and can make access to resources available.*" (Survivor, Advocate)<br>"*Community building and community engagement takes time, often we are looking for the quick fix. You cannot speed up the development of trust.*" (Community Leader, Advocate) |

with increased disparity at intersections of race, ethnicity, socioeconomic status, and sexual identity. The important influence of life stressors in the Black community, including the financial toxicity of a cancer diagnosis, was discussed throughout the forums. Finally, coping mechanisms and family relationships within the Black community were contributors to lived experiences.

Forum panelists shared common views and experiences related to the second theme that addressed the *contribution of healthcare providers and systems to racial disparity in BC survivorship*. Poor communication, provider bias, and lack of support were described. Forum panelists emphasized that concordance and reduced power differential between healthcare providers and patients are critical to increasing relatability, trust-building, and reducing disparity.

In the third theme, forum panelists addressed *models of care and research considerations to reduce racial disparity*. Panelists agreed that navigation support that is relatable, accessible, and offered to all patients would reduce racial disparity in survivorship. Specifically, there was consensus that navigation models that address treatment adverse effects and survivorship extending into the BC survivorship phase could reduce disparity. There was also agreement among panelists that universal application of the *Prospective Surveillance Model of Rehabilitation for Women with Breast Cancer* [16, 30] could reduce disparity in BC survivorship. The model was designed to guide screening and management of physical treatment adverse effects, as well as education and exercise. Throughout the forums, there was strong accordance about the critical importance of building community partnerships for survivorship services and research. Care and programs must be culturally relevant, collaborative, sustainable, and lift and empower the community. Forum panelists strongly vocalized the importance of the inclusion of voices of Black cancer survivors in community-based participatory research aimed at reducing survivorship disparity.

## Discussion

This study uniquely includes perspectives from Black BC survivors, health care providers, and researchers surrounding root causes, lived experiences, and potential solutions related to disparity in BC survivorship. There were no major differences in perspectives between panelists based on their primary expertise as a survivor, clinician, researcher, or advocate.

Cultural and historical mistrust of the healthcare system within the Black community has been documented as one of the barriers to adequate BC care [31, 32]. This inclination coupled with barriers to care created by systemic racism and socioeconomic factors contribute to the inferior outcomes in Black women [32]. Structural and societal inequities, including redlining, have been shown to be associated with BC mortality [33] and presumably, survivorship outcomes. Separately and cumulatively, these issues may result in failure to seek medical attention for health symptoms, refusal to participate in screening and detection efforts, lack of follow-through with treatment recommendations, and lack of participation in clinical trials.

The influence of life stressors in the Black community, including the financial toxicity of a cancer diagnosis, is reflected in the literature. Vulnerability related to one's socioeconomic situation, employment concerns, and instability in family systems are risk factors that contribute to the disparity [12]. Life stressors were a significant issue for Black survivors and included financial stress, medical bills, and greater environmental and role performance issues than White counterparts [21].

Coping responses of women of color were strongly affected by concerns regarding caring for close relatives such as spouse, children, and aging parents, not wanting to burden these people with their diagnosis [10, 12]. Cultural issues may include fatalistic beliefs about illness and disease, spiritual beliefs such as that "God will take care of this" may also contribute [31]. In a qualitative descriptive study that explored BC survivorship among 155 Black individuals, survivorship meant having a strong spiritual base, thriving, being resilient, and being altruistic [34]. Research has shown that Black women are more likely than White women to use spirituality as a coping tool around treatment decisions, adverse effects, intimacy, and body image concerns [10, 11, 35]. The importance of spirituality as it relates to BC survivorship was not a theme that emerged from the forums. This may be due to questions asked, individuals participating, and the public nature of the forums (Table 3).

When examining bias in the healthcare system, there is a tendency to focus on Black patients' mistrust rather than the racism of healthcare providers and within systems [36]. Perceptions of lack of support from providers, racism, and poor communication have been documented in the literature. The quality of the provider-patient relationship has been reported to be less than adequate by Black BC survivors [21]. Individual clinician communication, particularly with diverse patients, may contribute to disparity through implicit or explicit bias, cultural incompetency, and lack of skill to facilitate shared decision-making [37].

There is extensive evidence of racial inequity in healthcare and outcomes in the USA, and clinician biases have been shown to contribute to this. A large systematic review and meta-analysis found that many physicians, regardless of specialty, demonstrate a preference for White people [38]. Two lower quality studies reported a relationship between implicit bias and decision-making, and further research is needed to investigate the relationship between bias and

**Table 3** Forum questions

| | |
|---|---|
| First forum | 1. Tell us why you are passionate about this topic. What is your personal and/or professional experience related to disparity in survivorship experienced by Black women?<br>2. What additional barriers to survivorship support do Black breast cancer survivors face?<br>3. What do you see as the impact of these magnified survivorship issues on a Black woman, her family and the community and society at large?<br>4. What specific actions need to be taken to reduce the disparity in breast cancer survivorship that exists for Black women? |
| Second forum | 1. In the first forum, we delved into the many contributing factors to racial inequities in breast cancer survivorship outcomes. Today, we will delve into how to engage and work alongside Black communities to increase access to rehabilitation and exercise care. Tell us a bit about how your life and work experience contributes to today's conversation about community engagement as a solution to enacting change in cancer survivorship outcomes for Black women.<br>2. What is your personal and/or professional experience related to disparity in survivorship experienced by Black women?<br>3. Could you talk about your experience with and the role of community engagement by rehabilitation professionals? How can this be applied to solutions for equitable cancer survivorship?<br>4. The Center for Black Women's Wellness is a community-based, family service center committed to improving the health and well-being of underserved Black women and their families. What lessons can we learn from your experience and organization [Atlanta's Center for Black Women's Wellness] as we explore potential solutions and models that will reduce disparity in breast cancer survivorship?<br>5. What is the first step in engaging communities and rehab professionals to work alongside communities that will result in meaningful and sustainable change in breast cancer survivorship?<br>6. What local and national resources and buy-in (e.g., financial, community, education, training for rehab professionals, stakeholders at the table, etc.) are needed to move this initiative forward? What do you anticipate being the barriers to move forward? |
| Third forum | 1. Talk to us about your experience, and what makes you passionate about breast cancer survivorship and racial disparity.<br>2. In past forums, we have identified models of care which, if instituted as standard of care in the USA could reduce disparity in survivorship outcomes. Several programs including the Prospective Surveillance Model of Breast Cancer Rehabilitation and focused Navigation have been proposed as models that could reduce disparity. What are your thoughts about these approaches, and other models, that could result in more equitable care?<br>3. Inattention to cancer impact, treatment side effects, patients' needs, unconscious bias, and lack of awareness of the role of rehabilitation were identified in our first two forums as barriers within the healthcare system that contribute to disparity in survivorship outcomes. What needs to change within the healthcare and research communities—individually and broadly—to reduce disparity in breast cancer survivorship? How can we facilitate these necessary changes?<br>4. What specific policies or funding for survivorship care need to be changed or enforced at a national level to reduce disparity?<br>5. How would this intersect with the critical importance of culturally appropriate and community-based solutions identified in our second forum? |
| Fourth forum | 1. A breast cancer diagnosis deeply impacts mind and body. Racial bias, feeling unheard, lack of relatability and cultural competency of healthcare team, reluctance to complain about treatment side effects impact the support you received for these physical and emotional issues during and following your treatment?<br>2. In the first forum, we talked about the causes and impact of racial disparity in breast cancer survivorship. Can you reflect on the themes brought out during the forum and if they resonated with your thoughts and experience?<br>3. What did we miss or fail to emphasize with respect to the causes and impact of disparity in your opinion?<br>4. In the second and third forums, a number of community-based and national strategies were discussed that could potentially reduce racial disparity. In your opinion, which strategies are crucial to be enacted immediately to reduce disparity?<br>5. From a patient perspective, what additional strategies that were not addressed may help to reduce barriers to breast cancer rehabilitation and recovery care for Black women and men?<br>6. In your experience, what recommendations would you give to healthcare providers as far as better supporting the physical and emotional survivorship needs of Black individuals going through breast cancer treatment and beyond? |

racial disparity in healthcare [38]. A combination of low explicit and high implicit bias in the healthcare provider most negatively affects patient satisfaction with a medical encounter, likely due to the creation of dissonance and distrust [36]. White people who sincerely want to behave in a non-prejudiced manner often manifest interracial anxiety, attempting to avoid communication errors, which can reduce communication effectiveness [36]. Implicit bias was significantly related to patient-provider interactions, treatment decisions, treatment adherence, and patient health outcomes. Implicit attitudes were more often related to patient-provider interactions and health outcomes than treatment processes [39]. Further research is needed to explore racism encountered in treatment, support, and the work environment [12].

The issue of concordance between patients and providers is fueled by underrepresentation of racial and ethnic minorities in the US healthcare system and does not appear to be changing substantially [37]. Only 5% of active physicians [40] and 3.4% [41] of physical therapists in the USA are Black. In looking to the future, only about 7% of 2018–2019 medical school students in the USA were Black [40].

Universally applied models of support care for BC patients and survivors could reduce racial disparity.

Navigation models exist, but often lack attention to the physical and emotional impact of treatment. A survivorship navigation model that includes rehabilitation professionals aware of the physical and emotional impact of treatment and the role of rehabilitation and exercise have been successful [42]. Navigation must be culturally appropriate and intentional in addressing known disparity. Anticipatory guidance should be provided to address stressors and issues for Black survivors transitioning out of treatment [11]. Peer navigation with relatable survivors and support groups specific to Black women are also warranted [43].

Broad application of the Prospective Surveillance Model of Rehabilitation could reduce disparity in BC survivorship outcomes. The model was developed by an expert panel based on evidence supporting improved outcomes with early detection and management of impairment and functional issues [30]. It includes an early baseline assessment of impairment and function, ideally pre-operatively with ongoing intermittent follow-up assessment post-operatively and throughout the trajectory of care. As issues are identified, rehabilitation can be initiated early for optimum outcomes. Education and exercise are woven throughout the model. Implementation of the model has been shown to be an effective approach to identifying the need for rehabilitation as well as reducing and even preventing the impact of adverse effects, including in a group of Black women post-operatively [23, 44, 45].

The importance of the inclusion of Black cancer survivors' voices in community-based participatory research aimed at reducing survivorship disparity is echoed in the literature [12, 29]. Building collaborative community research partnerships is critical.

## Limitations

The six investigators independently identified themes from the four forums. The authors have presuppositions based on their lived experiences and an awareness of the literature that there is racial disparity in BC survivorship in the USA. In addition, the overt goal of the forums was to shed light on and seek solutions to reduce racial disparity in BC survivorship. These issues may have biased the authors analytical lens and the subsequent themes generated [24]. Narratives are complex acts of speech, are constructed contexts, and draw on shared narrative resources. Three of the investigators were involved in forum participant selection and development of questions that could have biased the responses. While narratives are always interactions with an audience, the format, public nature, and interaction of panelists with each other and the moderator may have influenced data collected during the forums [35].

## Conclusion

The forums produced compelling documentation of lived experiences of racial disparity in BC survivorship that have been described in the literature for nearly two decades. Potential solutions exist and must be enacted immediately to ensure equitable survivorship outcomes for Black individuals following a BC diagnosis.

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**Author's contribution** All authors contributed to the study conception, design, analysis, and manuscript review and editing. Jill M. Binkley wrote the first manuscript and all authors contributed to and edited subsequent manuscripts. All authors read and approved final manuscript. In addition to these roles, Jill M. Binkley and Lauren E. McCullough led funding acquisition.

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## Declarations

**Conflict of interest** The authors no relevant financial or non-financial interests to disclose. The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the Centers for Disease Control/the Agency for Toxic Substances and Disease Registry.

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