Health Behavior Research

Volume 7
Number 4 *Special Issue: Mentorship to Advance Health Behavior Research*

Article 21

October 2024

Use of Co-Design to Identify Barriers to Health-Promoting Behaviors among African American Breast Cancer Survivors with Comorbid Obesity

Kelsey Sinclair
Indiana University Health & Wellness Design School of Public Health, kelsinc@iu.edu

Misty Hawkins
Indiana University Health & Wellness Design School of Public Health, miahawki@iu.edu

Maresa Murray
Indiana University Applied Health Sciences School of Public Health, marjmurr@indiana.edu

See next page for additional authors

Recommended Citation

Sinclair, Kelsey; Hawkins, Misty; Murray, Maresa; McChristian, Jennifer; Werner, Nicole; Ramly, Edmond; Zoh, Roger; Allen-Watts, Kristen; Ballinger, Tarah; and Johns, Shelley (2024) "Use of Co-Design to Identify Barriers to Health-Promoting Behaviors among African American Breast Cancer Survivors with Comorbid Obesity," *Health Behavior Research*: Vol. 7: No. 4. https://doi.org/10.4148/2572-1836.1256

Use of Co-Design to Identify Barriers to Health-Promoting Behaviors among African American Breast Cancer Survivors with Comorbid Obesity

Abstract

Approximately 90% of African American patients with newly diagnosed breast cancer have multimorbidity – with obesity as one of the most common conditions. Obesity is related to negative impacts across all aspects of cancer care as well as more adverse side effects of cancer treatment. African American breast cancer survivors (BCS) show higher incidences of chronic conditions, like obesity, with barriers to body wellness. Lifestyle interventions can improve survivorship outcomes, but most have not been adapted to African American BCS needs. The purpose of this research is to explore and honor the lived experiences of breast cancer survivorship among African American women with obesity to better understand their experiences and perceptions of how their cancer journey intersects with other health behaviors and to identify barriers to health behaviors. A co-design approach with five participants was used to understand specific barriers to a healthy weight and lifestyle as well as potential solutions that would benefit African American or Black BCS entering an evidence-based lifestyle intervention that targeted weight and body wellness. Participants completed one co-design session for problem identification. This initial session identified the participants' most impactful cancer- and non-cancer-related barriers to building health behaviors. Cancer- and non-cancer-related carriers to a healthy lifestyle were identified from artifact creation and affinity diagramming for intensity and frequency. Top cancer-related barriers were pain and fatigue related to cancer treatment and its side effects. Non-cancer related barriers included time and responsibilities, nutrition, exercise, and the definition of health used by medical professionals. Both cancer-related and non-cancer related barriers were identified in contributing to difficulty in maintaining health behaviors. Further research should examine how these barriers can be addressed in lifestyle interventions targeted to African American BCS.

Keywords

co-design, multimorbidity, obesity, breast cancer, African American, health equity

Acknowledgements/Disclaimers/Disclosures

We would like to acknowledge the THRIVE NOW co-design participants for their courageous sharing, brilliant minds, and generous hearts. We also are indebted to Kelli Norton for her meticulous research leadership, Tayler Gowan and Madison Schwarz for their tireless transcription skills, and Jennifer West for her invaluable assistance with survey development and recruitment efforts.

Authors

Kelsey Sinclair, Misty Hawkins, Maresa Murray, Jennifer McChristian, Nicole Werner, Edmond Ramly, Roger Zoh, Kristen Allen-Watts, Tarah Ballinger, and Shelley Johns

Use of Co-Design Approaches to Identify Barriers to Health-Promoting Behaviors among African American Breast Cancer Survivors with Comorbid Obesity

Kelsey Sinclair, MA
Misty A.W. Hawkins, PhD
Maresa Murray, PhD
Jennifer McChristian, MSW, DSW, LCSW
Nicole E. Werner, PhD
Edmond Ramly, PhD
Roger Zoh, PhD
Kristen Allen-Watts, PhD
Tarah Ballinger, MD
Shelley A. Johns, PsyD, HSPP, ABPP*

Abstract

Approximately 90% of African American patients with newly diagnosed breast cancer have multimorbidity – with obesity as one of the most common conditions. Obesity is related to negative impacts across all aspects of cancer care as well as more adverse side effects of cancer treatment. African American breast cancer survivors (BCS) show higher incidences of chronic conditions, like obesity, with barriers to body wellness. Lifestyle interventions can improve survivorship outcomes, but most have not been adapted to African American BCS needs. The purpose of this research is to explore and honor the lived experiences of breast cancer survivorship among African American women with obesity to better understand their experiences and perceptions of how their cancer journey intersects with other health behaviors and to identify barriers to health-promoting behaviors. A co-design approach with five participants was used to understand specific barriers to a healthy weight and lifestyle as well as potential solutions that would benefit African American or Black BCS entering an evidence-based lifestyle intervention that targeted weight and body wellness. Participants completed one co-design session for problem identification. This initial session identified the participants' most impactful cancer- and non-cancer-related barriers to building health behaviors. Cancer- and non-cancer-related barriers to a healthy lifestyle were identified from artifact creation and affinity diagramming for intensity and frequency. Top cancer-related barriers were pain and fatigue related to cancer treatment and its side effects. Non-cancer related barriers included time and responsibilities, lack of nutritional information and culturally, medically sensitive exercise resources, as well as restrictive definitions of health used by medical professionals. Both cancer-related and non-cancer-related barriers were identified as contributing to difficulty in maintaining health behaviors. Further research should examine how these barriers can be addressed in lifestyle interventions targeted to African American BCS.

Keywords: cancer survivorship, obesity, fat loss, fatigue, pain, co-design methods, health equity

*Corresponding author may be reached at sheljohn@iu.edu

Introduction

Breast cancer is the leading cause of cancer-related deaths among African American women. Additionally, African American breast cancer survivors (BCS) have an alarming 41% higher death rate compared to their white peers (American Cancer Society, 2022). The high rates

of cancer deaths in female African American BCS are more troubling considering their lower breast cancer incidence. African American women have particularly high co-occurrence of at least two chronic conditions (i.e., multimorbidity), which is a driver of these increased cancer-related deaths (Meneses et al., 2015). Obesity is a cardiometabolic disease that adversely impacts African American women with breast cancer – both because obesity leads to earlier development of multimorbidity and more complex multimorbidity (four+ comorbid diseases) and because weight bias undermines patient care (i.e., women with obesity are less likely to be screened for breast cancer) (De Pergola & Silvestris, 2013; Lee et al., 2019). Obesity-cancer multimorbidity also adversely impacts cancer treatment, as it is linked to more treatment-related side effects (De Pergola & Silvestris, 2013). Though this is a known and important issue, individuals with obesity are less likely to receive standard preventative care, further impacting cancer outcomes.

The impact of multimorbidity continues long after treatment is completed. Obesity is linked to an increased relative risk of recurrence of 40-50% (Martin et al., 2023) and a greater risk of tumors due to the metabolic impacts of obesity (Kiplagat et al., 2022). Cancer survivors with obesity are at an increased risk of developing more complex multimorbidity and developing other chronic conditions (Husain et al., 2019). African American BCS are shown to exhibit more chronic conditions, such as obesity, which can have deleterious effects on their quality of life and overall mortality (Husain et al., 2019; Ko et al., 2023). Specifically, central obesity and higher adiposity are associated with higher all-cause mortality among African American BCS (Bandera et al., 2021). Additionally, excess weight and body changes after treatment can further impact survivors' quality of life. Recommendations for cancer survivors include losing weight as a way of managing multimorbid risk. However, in general, African American women have more difficulty losing weight compared to their white counterparts (Fitzgibbon et al., 2012). These difficulties can be related to systemic socioeconomic deprivation in childhood and beyond and greater exposure to obesogenic environments, discrimination and stigma, and chronic stress which contribute to weight gain and weight maintenance behaviors (Kiplagat et al., 2022).

Although physical activity and nutritional interventions are the standard for treating obesity, qualitative studies have found that health guidelines for survivors are overlooked in cancer care as the adaptation of physical activity and nutritional recommendations for specific BCS populations, especially African American BCS, are not available (Patel-Kerai et al., 2017). This oversight is particularly troubling due to the adverse impact of obesity on cancer reoccurrence but also because African American BCS are less likely to meet physical activity requirements and are less likely to be recommended nutritional services (Burse et al., 2024). Further, lifestyle interventions can improve survivorship outcomes, but most lack cultural competence, and African American women are underrepresented in clinical trial samples for lifestyle interventions (Husain et al., 2019).

Given the vast health disparities experienced by African American BCS, the theoretical foundation of this research program, including this study report, is informed using a health equity framework. The theory developed by Chapman et al. (2023) explores the downstream impacts of experiencing intra- and inter-personal related racism and existing within structures of systematic racism such as healthcare policy and social and economic policy. The downstream effect impacts attitudes, behaviors, stress, and mood. These then impact the physiological systems which can impact oxidative stress, immune response, gene expression, DNA repair, and general inflammation, which impacts cancer incidence, mortality, and the risk of developing multimorbidity. We applied this framework as a foundation in our approach and in the overall study design (e.g., choice of an African American

facilitator in co-design to elevate cultural representation, to create safe spaces, and to counter exclusionary systems; planned inclusion of systems-relevant variables such as the Everyday Discrimination Scale (Williams, 1997); verifying coded results with the participants to ensure their voices were heard and heard with accuracy; oversight from African American health expert, etc.). The current study (and associated report) is the first in a series designed to enhance cancer care in the context of multimorbidity like obesity in underserved groups, and the equity framework informs both the current and future sessions/programming.

In sum, the purpose of this present study is to explore the lived experiences of breast cancer survivorship among African American women with obesity in order to better understand their experiences and perceptions of how their cancer journey intersects with other health behaviors. Specifically, this study aims to identify the barriers to changes in diet, physical activity, stress management, and/or other targets of lifestyle interventions and body wellness. While initially focusing on weight management as our target health behavior, we expanded to include behaviors related to body wellness more holistically given early feedback from our participants. Accordingly, we hope to better understand: What are the main barriers that African American BCS face when trying to achieve body wellness? By understanding these issues, we can begin to adapt existing evidence-based lifestyle interventions or create new interventions to meet the needs of African American BCS, particularly those living with comorbidities such as obesity. A co-design method (Simonsen & Robertson, 2013) was used to center and elevate the voices of individuals with lived experience (i.e., under-represented BCS with obesity), as described in detail below.

Methods

A co-design approach with five planned co-design participants was used to understand specific barriers to a healthy weight and lifestyle as well as potential solutions that would benefit African American or Black BCS entering an evidence-based lifestyle intervention that targeted weight and body wellness. This N = 5 sample was planned given that five participants are not only within the standard range of participants used in participatory co-design research (Simonsen & Robertson, 2013), but also were feasible to recruit and appropriately reimburse given the timeline and budget of the pilot funding. This study will inform future development of and trials testing adapted lifestyle interventions specifically designed for African American BCS and focus on the identified solutions provided by the initial co-design planning process. The protocol and procedures were approved by the Indiana University Institutional Review Board.

Research team and reflexivity

The larger research team included nine university academic mentors and one graduate student mentee. Concerning racial categories, research team members identified as two African American women, one Black woman, one Black man, one Middle Eastern man, one Native American-white woman, and four white women. With regards to body size, the team identified with a range of body frames: medium athletic, normal or average, petite/medium, a surgically altered overweight body, and a larger body (obese). None of the team members have had a personal cancer history, although several members have strong collaborations with the cancer survivor community. Because the first author mentee does not identify as African American, deliberate efforts were made by the diverse mentorship team to 1) ensure oversight and racial safety training/consultation from team members with expertise in African American health and wellness and 2) to center the voices and direct quotations from the African American participants so as not to deviate from or incorrectly represent their lived experience and

expression (i.e., to engage in cultural deference). The larger research team assisted with the study conceptualization, guidance on the co-design process, the review of study materials, data interpretation, and/or reporting on study findings.

With regards to the co-design sessions, specific consideration was given to the research team members in the room during the session to establish a trustworthy and psychologically safe environment between the researchers and participants. The primary facilitator has an extensive background in working with cancer survivorship and African American women's mental health and self-identifies as an African American woman. Additional members of the research team present have an established relationship with participants, although they do not identify as African American. Coding and transcribing of the co-design sessions were conducted by two female research assistants who identified as white; thus, results were relayed back to the African American co-design participants for accuracy checking and edits were made to correct any identified errors.

Co-Design Participants and Recruitment

Co-design participants meeting the following inclusion criteria were enrolled in the study: 1) aged 21-65; 2) had a BMI 30 through 45 kg/m^2; 3) identified as African American or Black; 4) had a diagnosis of stage I-IIIA breast cancer without evidence of distant disease (e.g., metastatic spread of cancer from its original location) at the time of the study; and 5) had completed surgery, radiation therapy, chemotherapy, and/or biologic therapy at least two weeks before beginning the study but within the past six years (ongoing endocrine therapy was allowed). Recruitment utilized an existing dataset of breast cancer survivors who have participated in previous research studies, thus employing an opportunistic sampling. Specifically, participants who indicated an interest in participating in future research studies were asked to participate in the co-design sessions. These participants had participated in a randomized controlled trial testing acceptance and commitment therapy for fear of recurrence in breast cancer survivors (R01CA255480, PI: Johns). From this sample, five female BCS who identified as African American or Black and met the eligibility criteria for the present study were selected to complete the co-design sessions.

Although we had a homogenous sample in regard to racial identity, we sought socioeconomic diversity in our co-designer sample; thus, our five participants were intentionally recruited with sociodemographic diversity in mind (e.g., differences in age, relationship and employment status, and education level). Our sample characteristics were: mean age 57.4 ± 4.03 years; relationship status (1 single, 1 divorced, 1 widowed, 2 married); educational attainment (1 some college/no degree, 3 bachelor's degree, 1 master's degree); employment (4 employed for wages full-time, 1 unable to work due to health/disability); income situations (1 do not have enough to make ends meet, 1 have just enough to make ends meets, and 3 comfortable); medical multimorbidity (mean number of medical conditions in addition to breast cancer was 4.0 ± 2.83). With regards to cancer history, co-designers were diagnosed with early-stage breast cancer (2 with stage I, 2 with stage II, and 1 with stage IIIA). Co-designers completed curative treatment for breast cancer an average of 44.8 ± 20.38 months prior to enrollment, with a few still receiving endocrine therapy. Completed treatments included surgery (4 co-designers), radiation therapy (3 co-designers), and/or chemotherapy (3 co-designers).

Co-Design Session for Problem Identification

The five enrolled African American BCS completed one co-design session for problem identification. This initial session identified the participants' most impactful cancer- and non-cancer-related barriers to building health behaviors. Future co-design sessions will focus

Figure 1

Word Clouds Summarizing Data from Affinity Diagrams about Barriers to Healthy Life

Summary: Top Cancer-related Barriers from Most to Least Intense/Frequent

1. **Pain/Neuropathy/Stiffness**
2. **Fatigue (physical and mental)**
3. Medication side effects
4. Family not supportive of healthier eating habits
5. Fear of not being able to participate
6. Clothing-Body Image Concerns
7. No desire (motivation)
8. Tightness in chest

Summary: Top Non-cancer-related Barriers from Most to Least Intense/Frequent

1. **Caring for others' needs/family responsibilities**
2. **Job stress/time**
3. Fatigue
4. Lack of motivation
5. Too busy
6. Injury
7. No support
8. Family not supportive of healthier eating habits
9. Hair
10. Personal definitions of health
11. Gym inaccessible
12. Challenge finding healthy recipes

on solution-generating and/or desired treatment adaptations and will be intentionally presented separately to allow comprehensive reporting and honoring of the identified barriers.

The first co-design meeting was in person and took place at the Regenstrief Institute, which is located near familiar hospital and cancer care systems. This location was determined for our study as most of the participants have attended community events at Regenstrief Institute and/or have received cancer care at the nearby hospitals. Further, one of the primary investigators of this project can ensure that there is a space for our participants that is private and equipped with audio recording.

Participants met at an agreed time in the afternoon, and the session was a total of two hours and 27 minutes. The session plan and content included the following steps: 1) Prior to the in-person session, priming prompts were sent to participants via email and/or phone (see below); 2) The session opened with introductions and an experiential mindfulness activity; 3) Co-designers shared their reflections/answers to the priming questions; 4) The primary co-design activity began with participants generating artifacts (i.e., written sticky notes) of key barriers to healthy behaviors; 5) An affinity diagramming process where the artifacts were organized by intensity and frequency of the barriers according to the co-designers evaluations; and 6) The session ended with a debrief.

Priming questions for the problem identification co-design question included: *How has your cancer journey impacted your relationship with your body, and with food, and with movement?*

Do you remember what the relationship with your body was prior to being diagnosed with cancer? Or is it the cancer diagnosis made you more aware of a relationship with your body?

What do you wish that people would know to be more healing? To create a more healing environment?

Notably, these questions assumed that the cancer journey did impact one's relationship with their body based on our reading of prior literature (Przezdziecki et al., 2013). However, we did deliberately try not to make assumptions about the direction of these changes (e.g., negatively or positively).

Next, the first question prompts to generate artifacts were: *On the sticky notes we've provided, write down as many barriers to healthy weight RELATED to your cancer survivorship as you can in the next 10 minutes. Think about things that have been barriers for you from diagnosis to treatment to survivorship.*

The second set were similar except they probed for barriers "NOT RELATED to your cancer survivorship" and to "Think about things that are barriers at home, work, in your relationships, and as you go about your daily life (also known as 'daily barrier'*)*." Participants were then asked to rank their identified barriers by intensity and frequency and to place them into one of four quadrants (e.g., affinity diagramming): 1) high intensity and frequency, 2) low intensity and frequency, 3) high intensity but low frequency, and 4) high frequency but low intensity. We then transcribed the written artifacts (i.e., sticky notes) onto electronic diagrams for ease of review and reporting to the group.

Data Analysis

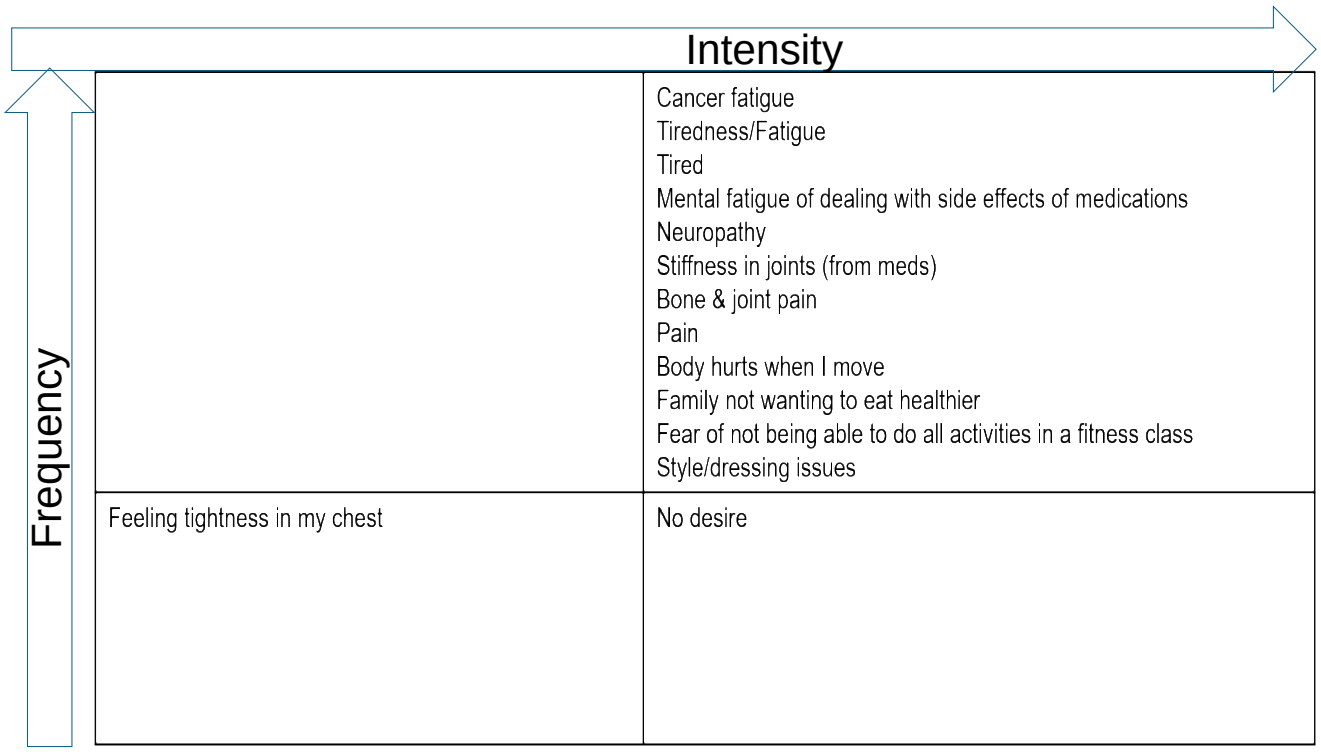
Artifact creation and affinity diagramming were done in sessions by the co-designers, then verified by review of the transcript and created artifacts and diagrams. The team later verified by sharing the diagrams and word clouds with the co-designers to ensure accuracy of the identified barriers list (see Figure 1).

Results

Five breast cancer survivors with excess adiposity who identified as African American or Black participated in the co-design sessions. Participants identified barriers to healthy weight/lifestyle that were organized into cancer- and non-cancer-related categories.

Figure 2

Affinity Diagrams Created from Participant Artifacts Describing Cancer-related Barriers to a Healthy Life



Cancer-Related Barriers

Participants identified that pain and fatigue were among the most prominent barriers to developing and maintaining health behaviors through discussions, artifact creation, and affinity diagramming (see Figure 2). The survivors relayed the experience of cancer treatment and the lasting side effects that continued to impact them into survivorship. Multiple survivors reported being physically hindered and unable to exercise due to medical procedures, pain, and low energy. One survivor elaborated by saying:

> It hurts to move. And I didn't have that before. And so I feel like, sometimes I feel like I'm 80 years old. You know? Its everyday is a reminder. When I get out of bed, I'm stiff - I get out of the car, when I stand up from this chair, I'm gonna be a little slow. So, the – I think the, but then they're like, "You should probably be exercising." Well, it hurts. Like - I just feel like energy level is just no. And I know it's like, "Okay, you should probably exercise and get more energy." But, I don't have energy to exercise. (SID 202)

Additionally, survivors identified direct health-related symptoms like neuropathy that also contributed to experiencing pain in movement. Regarding the fatigue experience, one survivor described the fatigue as "not just physical,…it's emotional, and it's spiritual, even. Because you get tired of that feeling of, you know, trying to be positive and trying to move forward" (SID 201). These lasting effects were also brought up in the experience of how survivors experience their bodies.

Accompanying the reported feelings of pain was also the experience of betrayal from their bodies. One survivor remarked that the residual side effects and pain are "a daily reminder that your body turned on you. And it, you know, it still could. You think about recurrence and whatnot. So I think that daily reminder, because again before my feet hit the floor… and so that's just a reminder of what happened to me (SID 201)." Another survivor reported that her body "has not felt the same or what was normal to me since my diagnosis and the loss of my breasts" (SID 204) and that there is a sense of grief that accompanies moving forward as a cancer survivor. While not being a direct barrier, this disconnection from the body may impact health behaviors. Importantly, while some women did express a lack of trust and negativity toward their bodies post-diagnosis, others found a deep appreciation for the strength of their body in carrying them through a stressful, frightening medical experience. Thus, it is essential not to assume that all body changes were aversive; some were indicative of a post-traumatic growth experience (Marziliano et al., 2020).

Non-Cancer Related Barriers

Non-cancer-related barriers fell into four main categories including responsibilities, nutrition, exercise, and the definition of health.

In both written and oral reports (see Figure 3) from participants, responsibilities and family obligations were reported as the most intense and consuming barrier. Participants noted that "the realities of life get in the way" when trying to build healthy behaviors. Participants particularly reported that responsibilities at home required time and energy. One survivor corrected the coder-summarized barrier of "caring for others" to mean the following:

> Caring for others doesn't literally mean I'm changing diapers or I'm doing something for someone. But sometimes the lack of prioritizing myself is what leads me to call it caring for others. By that, I mean like, I know I have to cook a meal and everybody has to eat it because I don't want to cook multiple things. So it's not so much that I'm just caring for other people, but it's that I'm not prioritizing what's best for me in that moment or I can't prioritize my time or my choices because I feel

> like others and their needs or their wants are a higher priority. (SID 201)

This theme was also seen in the introductions from the survivors. There was a general consensus that these survivors played the role of the "strong" figure in their lives. When asked what something that they wished others knew about her, one survivor shared that "sometimes they think I'm the strong one, and sometimes I'm weak" (SID 203). Another survivor shared that "I would say strong in a different way, strong in that I can like listen and take things on and offer, you know, resources" (SID 201).

Nutrition was also a common theme. This theme overlapped with the cultural theme that also came up. Nutrition was discussed as a point of confusion, and many survivors cited a lack of information provided to them regarding food choices. One survivor commented that she felt "confused about what I should eat, what is good for me" (SID 203). She elaborated that mixed messaging makes it difficult to determine what areas of nutrition and foods should be focused on. Nutrition label literacy was also mentioned as a barrier to changing food choices. One survivor mentioned that "not understanding how to read labels, as far as food in general," as well as how to make healthy food choices when grocery shopping has impacted her ability to create a healthy life (SID 202).

Nutrition was also brought up in ways that related to comfort. The participants reported that food also held emotional significance to them. This emotional significance of food made changing behaviors difficult. One survivor shared:

> I grew up eating certain foods, and it is hard to just stop eating those types of foods. These foods are what I am used to – they are familiar and comforting. Trying to cut them out of my life completely is very unenjoyable and hard to implement. How do I mentally shut off 50 years of bad eating to switch to more corrective eating? Is there something wrong with my willpower? (SID 204)

Another survivor reported similar feelings about wanting food that was comforting and enjoyable. This survivor expressed confusion regarding how to adapt healthy food into enjoyable food.

Non-cancer-related exercise barriers were also noted as a barrier to developing healthy movement patterns. One survivor reported that adaptable exercise was unavailable or hard to find. Specifically, survivors expressed a desire for exercise that is adapted for larger bodies and exercise that accounts for the pain that is commonly experienced during cancer survivorship. Swimming was brought up as an alternative form of exercise that has been suggested. However, one survivor reported that hair coverings, like swim caps, for African American women are unreliable or do not fit right. The need to fix and restyle hair after getting it wet, from water or sweat, was a noted barrier for these African American BCS given the financial and time costs of hair care in the community.

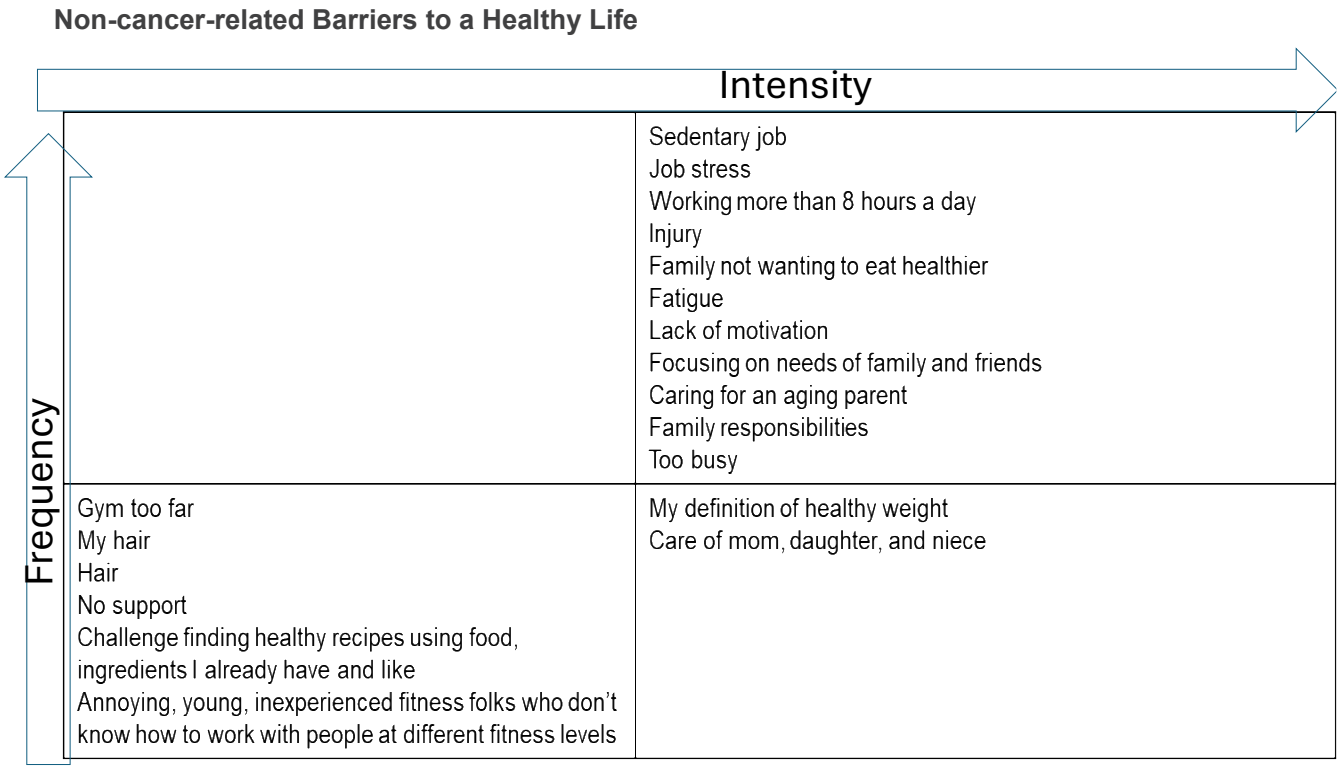
The final barrier discussed was the idea of health. The participants reported that their definition of healthy, and the definition of healthy by medical professionals, are not aligned. One survivor shared her experience:

> It is unhelpful that my doctors are overly focused on my weight and do not address my real-world challenges to implementing the things they tell me to do. I've had unpleasant experiences with doctors being shocked at my weight, telling me I don't fit the insurance chart, pressuring me to fit into their ideas and standards, dismissing my efforts, assuming all my issues are about my eating habits and weight, and not providing direction for implementing their instructions. (SID 204)

This participant identified the lack of support in defining her own idea of health and the

Figure 3

Affinity Diagrams Created from Participant Artifacts Describing Non-cancer-related Barriers to a Healthy Life



influence of this lack of support on the other barriers previously discussed.

Discussion

A co-design session was conducted with five African American BCS with excess adiposity as part of the problem-identification phase of a four-part participatory co-design process to adapt an evidence-based therapeutic lifestyle intervention. This first session explored barriers to creating and maintaining healthy behaviors. Barriers fell into two main categories: cancer-related and non-cancer-related.

Cancer-related barriers contained two primary subcategories relating to pain and fatigue. Pain related to treatment for breast cancer was reported to persist after completion of cancer treatment. This pain made survivors feel physically hindered, making exercise and motivation for movement very difficult. Fatigue also contributed to difficulties in movement due to its severity. This barrier to movement was also found in the non-cancer-related barriers, although in this context, the survivors were mostly discussing lack of resources. However, the lackluster resources related to the adaptation of movement to account for larger bodies as well as bodies with cancer symptoms. Pain and fatigue were primary barriers, and without proper adaptation of movement, BCS with excess adiposity have found it difficult to create a habit of healthy movement. Similar results have been found in previous studies with white BCS where the pain and fatigue associated with cancer treatment was a noted barrier to movement and physical activity (Przezdziecki et al., 2013; Marziliano et al., 2020). Such findings suggest that adaptations for physical activity that account for cancer-related symptoms would be appreciated across multiple racial groups. As discussed below, additional, more nuanced adaptations/accommodations to physical activity are also needed for factors unrelated to disease or multimorbidity such as differential time and stress regarding aspects of self-care (e.g., more time-consuming or costly hair care routines) or other care (e.g., expectations of emotional restraint, independence, and caretaking from the Strong Black Woman schema) (De Pergola & Silvestris, 2013; Lee et al., 2019; Donovan & West, 2015).

Regarding non-cancer-related barriers, time was one of the most cited. In this context, it was related to responsibility to family and to caring for others. One survivor phrased this as "not prioritizing" herself in that her needs and choices were not as valued or important as the needs and values of others around her. As discussed in the results, the idea of being strong was often associated with the idea of taking care of others. In this context, the expectation to be the models of resilience and masters of caretaking (Platt & Fanning, 2023) is related to being emotionally strong for those around them by being a support system or holding things together in stressful times. Previous literature has also found that the traditional gender roles of women interfere with health-promoting behaviors (Przezdziecki et al., 2013) in cancer survivors, but African American women experience more stress related to gender roles than their white counterparts due to the compounding effects of this Strong Black Woman concept (Marziliano et al., 2020, Parks & Hayman, 2024). While this concept was not directly named by the women, results indicate that this ideology may be impacting participants above and beyond traditional gender roles. With regards to physical activity, participants echoed barriers endorsed by the nearly 40-50% of African Women in non-cancer populations who avoid exercise at times due to hair-related issues (Hall et al., 2013) or thinking that their hair care practices are not "exercise-friendly."(Huebschmann et al., 2016). Additionally, nutrition, specifically a lack of nutritional information, was brought up as a barrier to healthy living. The survivors reported feeling that there was a lack of education regarding how to read nutrition labels and how to make healthy alternatives of food they liked so that they could find comfort in the food they were

eating. Resources related to understanding the adaptation of food and how to read food labels to inform healthy choices should be provided to assist in changing behaviors around food. Another qualitative study assessing nutrition barriers among cancer survivors also noted a lack of information as a barrier to healthy food choices. However, this lack of knowledge related to how to eat healthily, affordably, and cook healthier meals (Donovan & West, 2015). Defining health was also a noted barrier. Participants discussed that the medical focus on insurance standards of the body has hindered their care and their feelings toward building and maintaining health behaviors.

Overall, participants expressed wanting individualized treatment in their care. To create a less harmful healing space for these survivors, one survivor voiced wanting acknowledgment for the effort and progress survivors are making:

> I am trying**.** It is not helpful to hear your canned responses about what I should do. I know the things I need to do – eat less, move more – but unless you are going to give me ways to mentally and physically get over the barriers to achieving this, I don't want to hear it because I am already trying the best I can. (SID 201)

African American BCS have been harmed by being held to "cookie-cutter" standards of the medical community, which has led to and continues to contribute to inequities in cancer treatment and cancer survivorship. Future research should examine how to address these identified barriers and focus on specific solutions for African American BCS as they are differently nuanced.

Implications for Health Behavior Research

This study reveals significant gaps in cancer care that are disservices to African American BCS. Narratives provided by survivors revealed that care beyond initial cancer treatment is lacking even though cancer symptoms and side effects of care treatment continue to persist long after the initial treatment(s) have concluded. While this lack of continuity of care has been documented in previous cancer literature, the long-standing problem of how to specifically treat multimorbid obesity (or other related conditions) during survivorship has not been accounted for in ongoing care.

Explicitly, our study has revealed several gaps in knowledge among survivors on how to adjust and adapt diet and exercise for bodies that have fought cancer and survived while experiencing obesity. As African American BCS are more likely to be impacted by pain and are less likely to meet physical activity requirements, there must be a better adaptation of exercise and physical activity provided in survivorship care to account for pain-related symptoms. Specific nutritional information was also found to be lacking in survivorship care. Previous literature (Patel-Kerai, 2017; Burse et al., 2024; Keaver et al., 2023; Smith et al., 2017; Hefferon et al., 2013) has found that this is a known need among BCS. However, our survivors confirmed that it has not been adapted into cancer care standards. When examining dietary notices provided by leading cancer resources like the American Cancer Society (ACS) (Rock ey al., 2022; Bandera et al., 2021), the guidelines provided in this notice do not include cultural considerations and how food and movement may be impacted by these cultural needs. Additionally, there is a lack of examples of how to incorporate these healthy suggestions into practice. For example, the notice states that survivors should include a variety of foods, limit red and processed meats, incorporate plant-based foods, and many other suggestions, but does not provide examples of what meals falling within these guidelines could look like while still being culturally relevant. This creates a barrier as more energy is required to plan and execute these meals that may or may not be considered healthy, and cancer survivors noted that pain and fatigue deplete these energy stores. Further, within this guide, there are no

guidelines on how to read nutrition labels to critically evaluate food choices, which was a barrier specifically noted by our survivors. To provide just a few simple examples of specific and culturally informed nutritional guidance, our team has identified resources such as Patti LaBelle's Lite Cuisine cookbook as useful for identifying specific recipes to provide, (LaBelle, 2003) experiential activities on reading food labels, (Forman & Butryn, 2016) as well as information on levels of food processing (Petrus et al., 2021).

When examining the physical activity guidelines provided by the ACS, there are minimal examples of different types of exercise that are listed, and they typically do not account for cancer-related symptoms. There is a link to a separate document of an adjusted exercise plan for cancer-related symptoms, but the exercise types are not well explained to a layperson (i.e., the use of terms like "aerobic" and "resistance") and do not provide specific examples. A glaring gap in this resource is that pain is not generally acknowledged as a cancer-related symptom. As an example of a specific activity recommendation that is sensitive to cancer-related neuropathic pain, our team identified a series of YouTube exercise videos (GrowwithJo, 2022) using "seated cardio" in order to provide an option for a survivor with neuropathy in her feet.

In conclusion, informational resources are available, but the incorporation of clear, detailed plans with examples for how they might be used are lacking. We recommend that practitioners consider these barriers when recommending nutritional and physical intervention and offer clear, specific recommendations for implementation that can be used as a starting point. Specifically, behavioral scientists and practitioners need to consider that these barriers are far more complicated to overcome than just providing generic information or resources. African American BCS would like for there to be more understanding that the incorporation of this information into their daily lives is the biggest barrier they are facing – not the lack of understanding of information.

Another consideration revealed in this study is the lack of support felt by African American BCS. A common theme discussed in the co-design session were the responsibilities of caring for family members, friends, and other people in their lives. Many survivors reported being the "strong" one and not being able to prioritize their own needs (i.e., supporting the burden of the Strong Black Woman Stereotype) (Donovan & West, 2015; Platt & Fanning, 2023). This is another area that should be addressed by cancer care professionals as a barrier to receiving care. Acknowledgment of family members and support systems (or lack thereof) need to be incorporated into survivorship care.

While a co-design methodology was employed to gather data and the experiences of our survivors, there are some key limitations to this design. A main limitation is that our co-design group was comprised of only five members. This has been found to be acceptable in the co-design literature, but the small sample size can result in a lack of saturation. Despite some limitations, scientists and practitioners should consider co-designing sessions with the target population when building health behavior interventions for their target population. Literature and theory provide a foundation for assessing and addressing problems in building, maintaining, and changing health behaviors, but these lack nuance concerning the target populations' experiences. Thus, health behavior change interventions may be ineffective in achieving the desired health behavior goals. By hearing the experiences directly from members of the targeted community, researchers and practitioners can anticipate barriers and create a plan for overcoming them together using shared decision-making (Mhaimeed et al., 2023)

Discussion Questions

Our findings indicate that living in a body with obesity impacts the cancer journey and vice

versa. Our findings also indicate that being an African American woman with obesity uniquely impacts survivorship above and beyond obesity-cancer multimorbidity.

What approaches moving forward will best address both intersecting medical conditions and cultural considerations to enhance whole person care?

What other medical conditions and identities may increase care complexity for patients and require a tailored, shared decision-making approach to be sensitive and efficacious?

References

American Cancer Society. (2022). Breast cancer death rates are highest for African American women—again. *Breast Cancer Facts & Figures, 2022-2024*. Retrieved August 23, 2023, from https://www.cancer.org/research/acs-research-news/breast-cancer-death-rates-are-highest-for-African American-women-again.html

Bandera, E.V., Qin, B., Lin, Y., Zeinomar, N., Xu, B., Chanumolu, D., Llanos, A.A., Omene, C.O., Pawlish, K.S., Ambrosone, C.B. & Demissie, K. (2021). Association of body mass index, central obesity, and body composition with mortality among Black breast cancer survivors. *JAMA Oncology*, *7*(8), 1186-1195. https://doi.org/10.1001/jamaoncol.2021.1499

Burse, N. R., Cuffee, Y. L., Wray, L. A., Chinchilli, V. M., Lengerich, E. J., & Schmitz, K. H.(2024). Exploring quality of life experiences and concerns of Black breast cancer survivors: A narrative approach. *Journal of Cancer Education*, *39*(1), 96-102. https://doi.org/10.1007/s13187-023-02381-x

Chapman, C., Jayasekera, J., Dash, C., Sheppard, V., & Mandelblatt, J. (2023). A health equityframework to support the next generation of cancer population simulation models. *JNCI Monographs, 2023*(62), 255-264. https://doi.org/10.1093/jncimonographs/lgad017

De Pergola, G., & Silvestris, F. (2013). Obesity as a major risk factor for cancer. *Journal ofObesity*, *2013*, 1-7. https://doi.org/10.1155/2013/291546

Donovan, R. A., & West, L. M. (2015). Stress and mental health: Moderating role of the strongBlack woman stereotype. *Journal of Black Psychology*, *41*(4), 384-396. https://doi.org/10.1177/0095798414543014

Fitzgibbon, M. L., Tussing-Humphreys, L. M., Porter, J. S., Martin, I. K., Odoms-Young, A., &Sharp, L. K. (2012). Weight loss and African-American women: A systematic review of the behavioural weight loss intervention literature. *Obesity Reviews*, *13*(3), 193-213. https://doi.org/10.1111/j.1467-789X.2011.00945.x

Forman, E. M., & Butryn, M. L. (2016). Labels, planning, and calorie accounting. In *Effectiveweight loss: An acceptance-based behavioral approach, clinician guide* (pp. 31-36). Oxford University Press.

GrowwithJo. (2022). Sitting dance workout [Full body chair exercises].YouTube. https://www.youtube.com/watch?v=KwouzanR8SM

Hall, R. R., Francis, S., Whitt-Glover, M., Loftin-Bell, K., Swett, K., & McMichael, A. J. (2013).Hair care practices as a barrier to physical activity in African American women. *JAMA Dermatology*, *149*(3), 310-314. https://doi.org/10.1001/jamadermatol.2013.1946

Hefferon, K., Murphy, H., McLeod, J., Mutrie, N., & Campbell, A. (2013). Understandingbarriers to exercise implementation 5-year post-breast cancer

diagnosis: A large-scale qualitative study. *Health Education Research, 28*(5), 843-856. https://doi.org/10.1093/her/cyt083

Huebschmann, A. G., Campbell, L. J., Brown, C. S., & Dunn, A. L. (2016). "My hair or myhealth:" Overcoming barriers to physical activity in African American women with a focus on hairstyle-related factors. *Women & Health, 56*(4), 428-447. https://doi.org/10.1080/03630242.2015.1101743

Husain, M., Nolan, T. S., Foy, K., Reinbolt, R., Grenade, C., & Lustberg, M. (2019). Anoverview of the unique challenges facing African-American breast cancer survivors. *Supportive Care in Cancer, 27*(2), 729-743. https://doi.org/10.1007/s00520-018-4545-y

Keaver, L., Douglas, P., & O'Callaghan, N. (2023). Perceived barriers and facilitators to ahealthy diet among cancer survivors: A qualitative exploration using the TDF and COM-B. *Dietetics, 2*(1), 123-139. https://doi.org/10.3390/dietetics2010010

Kiplagat, K., Antoine, F., Ramos, R., Nahid, M., Forte, V., Taiwo, E., Godfrey, K., Butryn, M. & Phillips, E. (2022). An acceptance-based lifestyle intervention in Black breast cancer survivors with obesity. *Journal of Immigrant and Minority Health, 24*(1), 1-11. https://doi.org/10.1007/s10903-021-01261-0

Ko, N. Y., Fikre, T. G., Buck, A. K., Restrepo, E., & Warner, E. T. (2023). Breast cancersurvivorship experiences among Black women. *Cancer, 129*(S19), 3087-3101. https://doi.org/10.1002/cncr.34634

LaBelle, P. (2003). *Patti Labelle's Lite Cuisine: A Cookbook*. Penguin.

Lee, K., Kruper, L., Dieli-Conwright, C. M., & Mortimer, J. E. (2019). The impact of obesity onbreast cancer diagnosis and treatment. *Current Oncology Reports, 21*(5), 1-6. https://doi.org/10.1007/s11912-019-0787-1

Martin, K.J., Denyse, T., Pageot, Y.K., Kim, J.H., Owoyemi, P., DeLuz, K.D. & Stanton, A.L. (2023). "I'm fighting for my life": Exploring interactions between Black women with breast cancer and healthcare providers. *Qualitative Health Research, 33*(8-9), 753-764. https://doi.org/10.1177/10497323231168581

Marziliano, A., Tuman, M., & Moyer, A. (2020). The relationship between post-traumatic stressand post-traumatic growth in cancer patients and survivors: A systematic review and meta-analysis. *Psycho-Oncology, 29*(4), 604-616. https://doi.org/10.1002/pon.5314

Meneses, K., Benz, R., Azuero, A., Jablonski-Jaudon, R., & McNees, P. (2015). Multimorbidityand breast cancer. *Seminars in Oncology Nursing, 31*(2), 163-169. https://doi.org/10.1016/j.soncn.2015.02.004

Mhaimeed, N., Mhaimeed, N., Mhaimeed, O., Alanni, J., Burney, Z., Elshafeey, A., Laws, S.A. and Choi, J.J (2023). Shared decision making with Black patients: A scoping review. *Patient Education and Counseling, 110*, 107646. https://doi.org/10.1016/j.pec.2023.107646

Parks, A. K., & Hayman, L. L. (2024). Unveiling the strong Black woman schema—Evolutionand impact: A systematic review. *Clinical Nursing Research, 33*(5), 395-404. https://doi.org/10.1177/10547738241234425

Patel-Kerai, G., Harcourt, D., Rumsey, N., Naqvi, H., & White, P. (2017). The psychosocialexperiences of breast cancer among Black, South Asian, and White survivors: Do differences exist between ethnic groups? *Psycho-Oncology, 26*(4), 515-522. https://doi.org/10.1002/pon.4187

Petrus, R. R., do Amaral Sobral, P. J., Tadini, C. C., & Gonçalves, C. B. (2021). The NOVAclassification system: A critical

perspective in food science. *Trends in Food Science & Technology*, *116*, 603-608. https://doi.org/10.1016/j.tifs.2021.08.010

Platt, L. F., & Fanning, S. C. (2023). The strong Black woman concept: Associated demographiccharacteristics and perceived stress among Black women. *Journal of Black Psychology*, *49*(1), 58-84. https://doi.org/10.1177/00957984221096211

Przezdziecki, A., Sherman, K. A., Baillie, A., Taylor, A., Foley, E., & Stalgis-Bilinski, K. (2013). My changed body: Breast cancer, body image, distress, and self-compassion. *Psycho-Oncology, 22*(8), 1872-1879. https://doi.org/10.1002/pon.3230

Rock, C. L., Thomson, C. A., Sullivan, K. R., Howe, C. L., Kushi, L. H., Caan, B. J., Neuhouser, M. L., Bandera, E. V., Wang, Y., Robien, K., Basen-Engquist, K. M., Brown, J. C., Courneya, K. S., Crane, T. E., Garcia, D. O., Grant, B. L., Hamilton, K. K., Hartman, S. J., Kenfield, S. A., Martinez, M. E., … McCullough, M. L. (2022). American Cancer Society nutrition and physical activity guideline for cancer survivors. *CA: a cancer journal for clinicians*, *72*(3), 230–262. https://doi.org/10.3322/caac.21719

Simonsen, J., & Robertson, T. (Eds.). (2013). *Routledge international handbook of participatorydesign* (Vol. 711). Routledge. https://doi.org/10.4324/9780203108543

Smith, L., Croker, H., Fisher, A., Williams, K., Wardle, J., & Beeken, R. (2017). Cancersurvivors' attitudes towards and knowledge of physical activity, sources of information, and barriers and facilitators of engagement: A qualitative study. *European Journal of Cancer Care*, *26*(4), e12641. https://doi.org/10.1111/ecc.12641

Williams, D. R. (1997). Measuring discrimination resource. *Psychology*, *2*(3), 335-351.