



“I Beat Cancer to Feel Sick:” Qualitative Experiences of Sleep Disturbance in Black Breast Cancer Survivors and Recommendations for Culturally Targeted Sleep Interventions

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Abstract

Background Sleep disturbance is common and distressing among cancer survivors. Black breast cancer survivors (BBCS) suffer disproportionately from sleep disturbance, yet there is limited research on how to address this issue.

Purpose This study aimed to understand the multifaceted experiences of sleep disturbance among BBCS and how to culturally target a mobile health (mHealth) intervention to improve sleep outcomes in BBCS.

Methods Semi-structured interviews were conducted in a purposive sample of 10 BBCS. Interviews were audio-recorded, transcribed, and coded for key barriers to sleep and potential solutions to incorporate into behavioral interventions using NVivo 12. Inductive applied thematic analysis techniques were employed to identify emergent themes.

Results Ten BBCS (mean age = 54, *SD* = 10) described their experiences of sleep disturbance with themes including: (1) barriers to quality sleep (e.g., cancer worry, personal responsibilities), (2) psychosocial impacts of sleep disturbance (e.g., fatigue, distress), and (3) commonly used strategies to improve sleep. The second section discusses suggestions for developing mHealth interventions to improve sleep for BBCS including: (1) feedback on an existing mHealth intervention and (2) intervention topics suggested by BBCS.

Conclusions Our findings highlight the challenges associated with sleep disturbance in BBCS. Participants report culturally targeted mHealth interventions are needed for BBCS who experience chronic sleep disturbance that affects their overall quality of life. These interventions should address coping with sleep-related issues relevant to many breast cancer survivors and BBCS (e.g., sexual intimacy, fear of cancer recurrence) and should incorporate intervention strategies acceptable to BBCS (e.g., prayer, meditation).

Keywords: Cancer · Oncology · Sleep · Quality of life · Patient-Reported Outcomes · Black or African American cancer survivors · Survivorship · mobile health (mHealth)

Introduction

Sleep disturbance is a growing public health concern among cancer survivors. Breast cancer accounts for the highest cancer incidence in the USA [1], and breast cancer survivors (BCS) report rates of sleep disturbance as high as 42% at 18 months after diagnosis [2]. Black BCS (BBCS) have a particularly high burden of sleep disturbance. Rates of clinically significant sleep disturbance among BBCS are as high as 53%–61% [3]. Research shows that disparities in sleep disturbance are evident even before starting cancer treatment [4] and may be

related to other disparities observed among BBCS, such as worse quality of life, vasomotor symptoms, inflammation, and adiposity [5–7]. Despite these documented disparities, research on treating sleep disturbance among BBCS is limited. As a result, there is little empirical evidence on interventions to address sleep disturbance in this vulnerable population.

Healthcare providers typically focus on educating patients regarding sleep hygiene or prescribing medication to treat insomnia [8]. However, Cognitive Behavioral Therapy for Insomnia (CBT-I) is recommended as first-line treatment

for insomnia [9, 10] and is efficacious for improving sleep outcomes in cancer populations [11]. However, we are unaware of any trials demonstrating the efficacy of CBT-I among BBCS or any other Black cancer survivor population. Moreover, culturally targeted CBT-I interventions for Black populations are also lacking. One trial of a CBT-I intervention did not find attrition differences by race [12]. However, evidence from other chronic conditions shows that culturally targeting behavioral interventions to racial/ethnic minority groups improves intervention uptake and efficacy [13, 14]. Such targeting can account for nuances in various cultural groups that can enhance personal relevance of the intervention. Due to the widespread shortage of available clinicians with training in administering CBT-I [15, 16], self-help mobile health (mHealth) interventions may be an efficacious strategy for providing culturally targeted and accessible care to Black cancer survivors with sleep disturbance [17].

Consistent with Phase I of the ORBIT Model for Developing Behavioral Treatments [18], qualitative research is critical to the success of developing culturally targeted interventions that may help reduce disparities. This qualitative study aimed to explore BBCS experiences with sleep disturbance, describe BBCS-reported barriers to using CBT-I, as well as responses and beliefs regarding the development of mHealth behavioral interventions for sleep disturbance.

Methods

We report on qualitative data from a sequential mixed methods study [19] conducted from February through October 2020. Semi-structured in-depth interviews were used to prepare for adapting CBT-I for BBCS. The interview guide was developed by a team of experts with experience in qualitative methods, behavioral sleep medicine, and cancer survivorship. Using purposive sampling [20], BBCS were recruited among patients previously treated at Moffitt Cancer Center. Eligible patients were 20–75 years old, self-identified as Black or African American, had finished primary treatment for breast cancer (e.g., surgery, chemotherapy, and/or radiation) within the last 5 years, and reported difficulty sleeping ≥ 4 on a scale of 0–10. This study was approved by Advarra IRB (Pro00020603).

After obtaining informed consent, approximately 60-min interviews were conducted in-person or via videoconference. First, participants were given an overview of a web-based CBT-I intervention [21] for cancer survivors that was professionally translated from French to English. The overview of the intervention was delivered via a desktop or laptop computer. More information about the intervention is available elsewhere [22]. The web-based intervention has six weekly modules of content for participants to review. Each module begins with an animated video of a professor educating four individuals with cancer on etiology of insomnia and on treating insomnia with CBT-I. Each module then provides interactive text, images, and quizzes to educate participants on implementing CBT-I. The intervention also includes sleep diaries and graphs summarizing patient-reported sleep data. Interviewers used a semi-structured interview guide to assess the following: (a) participants' experiences with sleep disturbance, (b) barriers to using CBT-I, (c) perceptions of the existing web-based CBT-I intervention, (d) and recommendations for targeting

CBT-I to BBCS. Participants also completed a brief demographic questionnaire. Interviews continued until thematic saturation was reached, which was achieved when no new themes were identified in 10 consecutive interviews. Participants received \$50 gift cards as compensation for their time.

Interviews were audio-recorded, transcribed verbatim, and de-identified. NVivo 12 (Melbourne, Australia) was used for data management and analysis. Data were analyzed using applied thematic analysis techniques [23]. In weekly meetings, two graduate-trained qualitative analysts synthesized themes and subthemes within and across interviews to ensure a comprehensive understanding of the data. Inter-coder reliability was evaluated until Cohen's kappa reached 0.80, indicating substantial agreement [24].

Results

Demographic information is listed in Table 1 for the 10 women who participated. On an average, participants were 54 years of age and diagnosed 4 years before completing the interview. Nearly all (90%) were diagnosed with Stage 0 or Stage II breast cancer. Representative quotes are provided in Table 2.

Table 1. Characteristics of Black Breast Cancer Survivor Participants ($N = 10$)

Participant characteristic	N (%)
Age (M, SD)	54 (11)
Years since diagnosis (M, SD)	4.3 (1.0)
Years since completing treatment (M, SD)	3.7 (1.0)
Disease stage at diagnosis	
0/I	4 (40%)
II	5 (50%)
III	1 (10%)
Ethnicity	
Hispanic/Latina	0 (0%)
Not Hispanic/Latina	10 (100%)
Highest level of education	
High school, GED, or equivalent	3 (30%)
Technical or trade school	1 (10%)
2-year college degree	2 (20%)
4-year college/university degree	3 (30%)
Graduate, professional degree	1 (10%)
Employment status	
Employed full-time	6 (60%)
Employed part-time	0 (0%)
Looking for employment	1 (10%)
Homemaker	0 (0%)
Retired	3 (30%)
Marital status	
Divorced or separated	3 (30%)
Married	2 (20%)
Single	3 (30%)
Domestic partnership or civil union	1 (10%)
Widowed	1 (10%)

Table 2. Qualitative Themes, Subthemes, and Exemplar Quotes from Black Breast Cancer Survivors (BBCS)

Barriers to high quality sleep	<p><i>Cancer worry</i> “I think people don’t realize how, after having cancer, how stressful or how stressed you can be about worrying if it’s going to come back.”(Participant # 02)</p> <p><i>Personal responsibilities</i> “Sometimes when there’s a crisis or some things that are going on, it needs to be taken care of... a lot of people do look up to me... That can be something on my mind before I go to sleep.”(Participant # 05)</p>
Psychosocial impacts of sleep disturbance	<p><i>Decreased energy during the day</i> “I already had sleep issues before I had cancer. But after... it’s worse. I’m always tired... I just feel like, even though you beat cancer, a good thing, like what did I really beat? I beat cancer to feel sick.”(Participant # 13)</p> <p><i>Lower productivity</i> “I do get up early in the morning, and if I don’t sleep well, then I’m really sluggish and I’m not really that productive during the day.” (Participant # 05)</p> <p><i>Psychological distress</i> “My anxiety’s kicking because I’d be tired, and every little thing agitates me... I tend to get anxious a lot and I get on people’s nerves because I’m tired.”(Participant # 14)</p>
Commonly used strategies to improve sleep	<p><i>Nightly routines with electronics</i> “Some nights I turn on old TV shows that I’ve already watched...and I’m asleep, just like that.”(Participant # 14) “I just have to have something like that to make me fall asleep...Some background noise. No music or anything. Just something talking. And I have the radio right by my bed.”(Participant # 06)</p> <p><i>Sleep environment</i> “I try to make sure that the house is cool so I can rest comfortably.” “I try to have the house cool; very cool. Maybe around 66 [degrees], and that seems to help.”(Participant # 04)</p> <p><i>Staying active</i> “Those are, up and down, tiring work... I was working in a preschool. So, you know I deal with the children a lot, back and forth on the playground. So, by the time you get home, and you do your little cooking and laundry and whatever, you’re ready for bed around 9:30-10 pm. You get a good rest. And so when I wake up, I’m fresh and busted with energy when I get up the next morning.” (Participant # 11)</p>
Feedback on an existing mHealth CBT-I intervention	<p><i>Sleep hygiene and behaviors</i> “I think the main thing... would be to identify the cause of not having a good sleep hygiene program. That would be number one...I like the fact that they give you a lot of information about potential problems you may be having, and it gives you the opportunity to evaluate yourself and see where you fit in.” (Participant # 05)</p> <p><i>Sleep tracking</i> “This type of information can be used by doctors, like my cardiologist is asking me how I’m doing with my sleep. My therapist asking me, how my sleep is based on my anxiety. So it would be really quick and easy to pull this up and say, “The past, you know, three months I’ve had this poor sleep.” (Participant # 09)</p> <p><i>Smartphone preference over computer</i> “If it’s an app or it’s on my phone...then I’m going to be a little more engaged.” (Participant # 09) “More frequently because the other program that I’m using for weight loss is an app that I use, and I look at that every day.” (Participant # 05)</p> <p><i>Diverse representation</i> “From what I was able to see...it just looks not like a typical African American household. This seems more catered to Caucasians.” (Participant # 04) “If this is geared for an African American breast cancer survivor, most of the people... should represent us.” (Participant # 09)</p>
Intervention topics suggested by BBCS	<p><i>Anxiety and stress management</i> “Sometimes there’s nothing happening in my life and I just get anxiety. I mean, should I start humming or do yoga? Are there other techniques prior to going to bed to slow my mind down and make me unwind besides turning off the TV and phone?” (Participant # 14)</p> <p><i>Sexual intimacy</i> “I actually know I can’t have sexual intercourse with my husband, because it rejuvenates me. It puts him to sleep and wakes me up...So that definitely could be an issue for people.” (Participant # 09)</p> <p><i>Faith and religion</i> “The videos or maybe even having links or suggestions for meditation. Like something that helps relax a person...I do believe in prayer, so that helps a lot. I have a prayer session every night before I go to bed and when I wake up in the morning...It takes a lot of pressure off me when I pray to God; give him all my problems and I know he’ll work them out.” (Participant # 06)</p> <p><i>Medication interference with sleep</i> “I feel that someone needs to analyze the medicines that we’re on to make sure that that’s not what’s keeping us awake at night...If we’re on a combination of medicines, and the pamphlet that comes with it says ‘will cause insomnia.’ Not all people will read that...so they could be thinking that they’re struggling...personally, but it could actually be a medical reason.” (Participant # 09)</p>

Sleep Disturbance among Black Breast Cancer Survivors (BBCS)

Barriers to high quality sleep

Participants described their sleep as “inconsistent,” “interrupted,” and “not entirely restful.” Barriers to high

quality sleep included cognitive barriers and structural barriers. Commonly reported cognitive barriers included stress and anxiety inhibiting quality sleep, particularly thoughts related to fear of cancer recurrence. Participants often described how racing thoughts prevented them from falling asleep. For

those reporting waking during the night, worries made it difficult to fall back asleep. Structural barriers were related to work (e.g., waking up early or working night shifts) and role responsibilities (e.g., caring for children or helping friends).

Psychosocial impacts of sleep disturbance

Participants reported that lack of consistent, restful sleep negatively affected their quality of life and daily activities. Participants commonly described how sleep disturbance resulted in daytime fatigue and feeling “groggy,” “exhausted,” and “drained” during the day. Participants understood that their low energy levels directly impacted their ability to be productive and complete professional or personal work, often describing feeling “unmotivated.” One participant described how a lack of consistent sleep affected her motivation to engage in health behaviors (e.g., exercise), despite a desire to do so. In addition, some participants reported that a lack of restful sleep affected their daytime mood, including increased levels of daytime anxiety and irritability toward others. This, in turn, affected social functioning and relationships.

Commonly used strategies to improve sleep

Participants shared strategies they often used for better sleep. When discussing nightly routines, participants frequently mentioned the importance of avoiding television, cell phones, and other digital devices before bed. However, other participants discussed a reliance on electronics, including leaving the television or radio on to provide some distraction from racing thoughts while trying to fall asleep. Some participants described prayer or meditation as a calming part of their bedtime routine that helped them fall asleep, including reading religious and motivational texts. A few participants discussed using supplements or medications, such as melatonin, diphenhydramine, or muscle relaxers, with varied frequency of use. While participants described how these options can help in falling asleep, they also described how this can result in daytime dysfunction (i.e., morning grogginess). Some participants discussed how modifying their sleep environment helped them achieve higher quality sleep, such as keeping their room dark and cool. Lastly, staying active during the day was mentioned as being helpful in sleeping well at night. Some BBCS described noticing a benefit from physical activity during either unpaid work at home or paid work.

Suggestions for Developing mHealth Interventions to Improve Sleep for BBCS

Feedback on an existing mHealth CBT-I intervention

There was consensus that a culturally targeted mobile health (mHealth) sleep intervention could be very useful for improving sleep. Participants reported that sleep-focused educational modules would be most useful in gaining a general understanding of the etiology of their sleep disturbance as well as behavioral strategies to improve sleep. Most participants were receptive to logging sleep in a daily sleep diary; however, some found it inconvenient. BBCS discussed the benefits of viewing longitudinal sleep data, stating that insights into their sleep patterns could help them identify potential causes of sleep disturbance. One participant noted that having sleep data would be helpful to share with healthcare providers. BBCS overwhelmingly preferred intervention delivery via smartphone rather than via a desktop or laptop computer, stating that using a smartphone would facilitate ease and frequency of use. The possibility of wearable sensor devices to track sleep was also well-received. Participants reported this

would be more convenient, reliable, and effective than manual sleep diary records.

Intervention topics suggested by BBCS

Feedback was obtained about how to target mHealth sleep interventions to BBCS. Most participants recommended including techniques to alleviate racing thoughts while preparing for sleep. In addition to recommendations for managing everyday stress and anxiety related to family, work, and finances, interventions should specifically address stressors common in cancer survivors, particularly fear of recurrence. Most participants believed that addressing issues related to family and other relationships would also improve sleep. Some discussed how interventions should address unique demands for mothers in general and working mothers specifically. Other issues related to family and relationships were discussed during interviews, with participants describing the need to address the topic of sexual intimacy. While some participants did not see sexual intimacy as significantly related to sleep, others believed this would be an important topic to address. The topic of faith was brought up by several participants, describing it as an important part of their life in general and their experience with breast cancer. As mentioned above, several participants mentioned praying as an important part of their daily and nighttime routine, which they understood contributes to relaxation and quality sleep. Some participants also described how reading passages from the Bible or other faith-based materials can assist in relaxation before sleep. One BBCS suggested addressing the ways that medication and supplements can improve or worsen sleep. Last, participants emphasized the need for more diverse representation in the visual components of the mHealth intervention as related to race, ethnicity, and gender.

Discussion

This study adds to the limited knowledge from qualitative research investigating sleep disturbances in BBCS. This goal of the study was to understand the multifaceted experiences of sleep disturbance among BBCS. Participants also provided feedback on developing new interventions that may be useful for other populations as well as strategies for culturally targeting CBT-I to BBCS. Our findings highlight the need to incorporate feedback from the intended audience to ensure relevant content is provided.

The link between fear of cancer recurrence and sleep disturbance among BBCS is an important finding with implications for developing future interventions. Fear of cancer recurrence is commonly reported among BCS and has been identified as a precursor of insomnia [25, 26]. Moreover, studies have identified BBCS as being at greater risk for trauma-related emotions ultimately affecting their sleep patterns (e.g., intrusive thoughts affecting sleep latency) [27, 28]. Thus, fear of cancer recurrence and its associated emotional and cognitive consequences and may be particularly important to address in CBT-I interventions adapted for Black cancer survivors.

Participants in this study reported that lack of consistent, restful sleep negatively affected their quality of life and ability to carry out day-to-day activities, reporting decreased energy throughout the day, lower productivity, and increased psychological distress. This is consistent with other research that has found that sleep disturbance negatively impacts BCS overall quality of life, including deficits in ability to perform work and daily tasks, lower vigor or energy for daily activities, and worse emotional health [29]. Importantly, these relationships may be bidirectional and amplified among BBCS; compared

to White BCS, BBCS more often report role performance stressors in household, parental, and employment responsibilities [30, 31], which can in turn negatively impact sleep. Other qualitative research among cancer survivors has shown that sleep disturbance can persist long after treatment and affect temperament, sociability, physical well-being, cognitive functioning, relationships, and psychological well-being [32]. We extend these findings by specifically addressing the impacts of sleep disturbance for BBCS quality of life.

BBCS reported changing nightly routines, sleep environment, and daily habits to improve their sleep. These strategies align with established behavioral and pharmacotherapy interventions. For example, cognitive behavioral strategies such as developing good sleep hygiene (i.e., stimulus control) have been shown to be effective for improving sleep and can help cancer survivors cope with the psychological burden brought on by sleep disorders [33]. However, BBCS may spend more time in bed praying or watching TV prior to sleeping compared to other racial/ethnic groups [34]. Praying before bed was another reported strategy. Previous research shows midlife Black women are more likely than other racial/ethnic groups to use prayer to improve health [35], and Black women recommend spirituality and spiritual materials be included in behavioral interventions [36]. Prayer and religious meditation should be considered for inclusion among the relaxation strategies used in culturally targeted CBT-I. Participants also recommended including images of individuals representative of BBCS, with one participant noting the images and videos she viewed in the intervention overview seemed mostly catered to “Caucasians.”

mHealth interventions have been found to be effective for self-managing pain, psychological distress, fatigue, and sleep in cancer survivors [37]. BBCS in this study were very interested in utilizing a culturally targeted mHealth sleep disturbance intervention. Participants believed sharing sleep-tracking data with their care team would be beneficial for overall health; a benefit that has been discussed in previous research [38] as a way to better monitor patients, share information, and personalize clinical decision making in cancer care.

As others have pointed out [39], mHealth technologies offer a promising approach to improve support for cancer patients and survivors. There is a need to develop new targeted interventions to particular cultural, racial, and ethnic groups to ensure under-resourced communities and individuals find empirically supported treatment personally relevant. New interventions and modifications to existing interventions could help overcome additional barriers to effective symptom management among minority and underserved individuals [40]. These include limited access to providers, inadequate communication about quality of life issues (e.g., sleep disturbance), and communication barriers.

Strengths of this study include its focus on the underserved Black cancer survivors and that it is among the first qualitative analyses of the experiences of Black cancer survivors with sleep disturbance. Some limitations should be noted, including the small sample of patients treated at an NCI-Designated Comprehensive Cancer Center, which limits the generalizability of our findings. Another limitation is that participants only briefly reviewed the CBT-I intervention and were thus unable to speak from deep personal experience about using it on a daily basis. Nonetheless, their input regarding strategies for culturally targeting CBT-I to BBCS is instructive.

Future studies should aim to replicate and extend these findings among larger samples of Black cancer survivors and

among survivors of cancers other than breast cancer. Future studies should also incorporate these findings when culturally targeting interventions to reduce sleep disturbance among Black cancer survivors.

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Compliance with Ethical Standards

Authors’ Statement of Conflict of Interest and Adherence to Ethical Standards Authors BDG has consulted for SureMed Compliance and KemPharm outside this work and is an advisor for Elly Health outside this work. HSLJ has consulted for RedHill BioPharma, Janssen Scientific Affairs, and Merck and has received research grant funding from Kite Pharma. All procedures, including the informed consent process, were conducted in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000.

Author Contributions Carley Geiss: methodology, formal analysis, investigation, resources, writing – original draft, writing – review and editing. Melody N. Chavez: methodology, formal analysis, investigation, resources, writing – original draft. Laura B. Oswald: data curation, writing – review and editing. Dana Ketcher: conceptualization, methodology, writing – review and editing. Maija Reblin: conceptualization, methodology, writing – review and editing. Elisa V. Bandera: conceptualization, writing – review and editing. Josée Savard: conceptualization, resources, writing – review and editing. Eric S. Zhou: data curation, writing – review and editing. Rina S. Fox: data curation, writing – review and editing. Heather S.L. Jim: data curation, writing – review and editing. Brian Gonzalez, PhD: conceptualization, methodology, data curation, writing – original draft, writing – review and editing, supervision, project administration, funding acquisition.

Ethical Approval All procedures performed in this study were in accordance with the ethical standards of our institutional research ethics committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Slight deviation from this concerned informed consent, as explained below, but this was approved by our ethics committee.

Informed Consent Consent was obtained from all individual participants included in the study. However, given the nature of the research consent was not fully informed, although participants were aware that information was being withheld from them.

Transparency Statement

This observational study was not formally pre-registered. The analytic plan for this observational study was not formally pre-registered. De-identified data from this study are not available in a public archive. De-identified data from this study will

be made available (as allowable according to institutional IRB standards) by emailing the corresponding author. Analytic code used to conduct the analyses presented in this study are not available in a public archive. They may be available by emailing the corresponding author. Materials used to conduct the study are not publicly available.

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