

Developing a culturally tailored digital health intervention for insomnia in Black women

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Abstract

Insomnia disorder is highly prevalent among Black women. Cognitive-behavioral therapy for insomnia (CBT-I) is considered the optimal treatment, but very little efficacy research has been conducted in minority populations. Culturally tailoring intervention content may increase participant engagement and improve treatment outcomes. We culturally tailored an Internet-delivered CBT-I program (Sleep Healthy Using the Internet; SHUTi) for Black women. First, relevant stakeholders were identified. Semi-structured interviews were conducted after stakeholders completed each of the six SHUTi intervention sessions. Questions focused on improving program relatability and engagement for Black women. Key themes pertinent to peripheral, evidential, and sociocultural strategies for cultural adaptation were identified using thematic content analysis, and adaptation recommendations were developed. A total of 50 interviews, across 9 stakeholders, were conducted. Two overarching themes were identified: (i) there was limited visual African American representation, and (ii) there was a lack of diversity in the environments and lifestyles of the patient vignettes. Respondents provided peripheral, evidential, and sociocultural recommendations for program modifications, emphasizing the importance of race-concordant visual content and didactic content exploring the diverse cultural and social contexts in which insomnia occurs for Black women. As more diverse patients seek evidence-based insomnia treatment, digital health interventions must consider whether it is therapeutically important to address and tailor for cultural differences. Here, stakeholders made clear recommendations for taking cultural contexts into account to improve patient engagement with the program. Further research should work to understand the extent to which culturally tailored interventions are beneficial for health outcomes among minority populations.

Lay summary

Insomnia disorder is common among Black women. Cognitive-behavioral therapy for insomnia (CBT-I) is considered the gold standard treatment, but there have been few studies of this treatment in minority populations. Culturally tailoring the content of this intervention may increase a patient's willingness to seek this treatment and to respond better to the treatment. To study this, we conducted interviews with important stakeholders to determine how we should modify a proven online CBT-I intervention called Sleep Healthy Using the Internet (SHUTi). We were told that it was important to increase the amount of culturally specific visual content in the intervention materials, as well as make the stories told within the program more diverse. As we begin to see more diverse patient populations seeking evidence-based insomnia treatment, digital health interventions would be wise to consider whether developers should tailor elements of their program to recognize cultural differences.

Keywords: insomnia; Cognitive-Behavioral Therapy for Insomnia (CBT-I); cultural adaptation; Black women; qualitative research

Implications

Practice: Tailoring digital health interventions may be an important element of helping patients better engage in treatment.

Policy: Effective insomnia interventions should consider cultural/ethnic factors.

Research: Future research is needed to determine whether different cultural/ethnic groups may require different program adaptations.

Introduction

Women are approximately 1.5 times more likely than men to suffer from insomnia disorder [1, 2]. Consequently, the National Sleep Foundation has stated that there is a clear “need for sleep health improvement” among women in the USA [3]. This issue is particularly salient for Black women, as there are known sleep health racial disparities [4–6]. Compared to other racial groups, Blacks report shorter total sleep duration; lighter, more fragmented sleep [6–17]; and worse sleep quality [12, 18–20]. Indeed, between 15% and 19% of Black women are likely to be suffering from insomnia disorder, higher than the prevalence observed in a community-based sample of White women (12%) [21, 22]. Black women may be particularly vulnerable to the development and persistence of insomnia due to a range of factors including psychosocial stressors, such as racial discrimination, and the neighborhood environment [21, 23, 24].

Experts consider cognitive-behavioral therapy for insomnia (CBT-I) to be the optimal treatment for patients with insomnia disorder [25, 26]. CBT-I is a multi-component approach that targets the cognitions and behaviors that perpetuate an individual's insomnia, rather than managing the symptoms, as pharmacological treatment does [27]. Although CBT-I is a highly effective treatment, minority populations are consistently “less likely to initiate, continue or complete” behavioral health treatments such as CBT-I, and thus are more likely to experience poor health outcomes associated with suboptimal sleep [28, 29]. The reasons for this are poorly understood, as there has been very little efficacy research done for CBT-I in specific minority populations.

One path that has been proposed to address disparities in treatment engagement is to systematically tailor interventions to include culturally sensitive and relevant components consistent with patients' cultural experiences and values [29]. There is increasing evidence that tailoring biobehavioral interventions to different patient subgroups is an effective way to increase enrollment and engagement with intervention content, ultimately leading to better health outcomes [30]. While this work is novel in the domain of sleep, culturally adapted programs have been successfully implemented for a broad range of other health issues including diabetes prevention [31], smoking cessation [32], and improvements in diet and physical activity [33]. Meta-analyses have demonstrated a medium effect size ($g = 0.52$) favoring culturally adapted psychological interventions over un-adapted versions [34]. These findings may be the result of culturally tailored interventions being more respectful of patients' worldviews, providing what is perceived as more patient-centered care, encouraging connections with family and community support resources, and allowing patients to feel more comfortable with the intervention materials, thus facilitating disease education [35, 36].

In their seminal publication, Kreuter *et al.* [37] described key elements of cultural tailoring based on their model Common Strategies for Enhancing Cultural Appropriateness. Five specific strategies were outlined: (i) *peripheral*: designing materials to appeal to the patient group; (ii) *evidential*: enhancing relevance of the health issue by showing epidemiological evidence; (iii) *linguistic*: providing materials in the primary language of the target group; (iv) *constituent-involving*: drawing from the experiences of the patient population; (v) *sociocultural*: using cultural values, beliefs, and behaviors to provide context and meaning to the health messages.

Guided by this model, we culturally tailored a proven Internet-delivered CBT-I program called Sleep Healthy Using the Internet (SHUTi). SHUTi has been studied in multiple patient populations around the world, with consistent outcome data demonstrating its effectiveness in improving sleep [38–45]. Much like other CBT-I trials, this prior research was conducted mostly among non-Hispanic White adults. Primary findings from our randomized trial among Black women demonstrated that both the standard and culturally tailored versions of SHUTi were effective at improving insomnia. However, the culturally tailored version was significantly better at engaging Black women with the intervention; thus, patients were more likely to have better sleep by the end of the program [46].

The present report describes the process by which we tailored the Internet-delivered insomnia intervention for Black women, in hopes that our experiences can help inform future efforts to address sleep health disparities and help others attempting to culturally tailor a digital health intervention.

Methods

Nine stakeholders were identified to provide a representative sample of patients, providers, and researchers likely to be relevant for a Black woman with insomnia. With the goal of attaining a rich dataset across diverse participants [47], stakeholders included five Black women (one with a history of insomnia, another with participatory research experience, one participant in a longitudinal cohort study of Black women's health, one doctoral-level researcher focused on health disparities, and one research staff member involved in Black women's health research), a sleep physician whose patient population is comprised primarily of racial/ethnic minorities, a sleep psychologist with expertise in adapting CBT-I, an epidemiologist with an extensive research history in minority health, and a researcher in a leadership role at a national health organization. Our sampling strategy was designed to capture in-depth perspectives across a diverse set of stakeholders in order to confidently make the necessary and appropriate program adaptations. Indeed, our careful selection of the nine stakeholders allowed us to capture sufficient information-rich cases [48]. As shown in Fig. 1, all stakeholders met during a kick-off meeting in May 2018, during which team members were introduced and the study background was presented. We introduced SHUTi by highlighting the following points:

- The program delivers the core tenets of CBT-I, focusing on five treatment components: sleep restriction, stimulus control, cognitive restructuring, sleep behaviors, and relapse prevention.
- It is delivered online over six sessions that occur over a period of roughly 6–8 weeks. SHUTi content is metered out over time, with each intervention session made available 1 week after the completion of the previous session.
- The web-based platform is fully automated and is designed to not require external support once the individual with sleep problems has started treatment.
- The intervention includes a variety of interactive features, including personalized goal-setting, graphical feedback

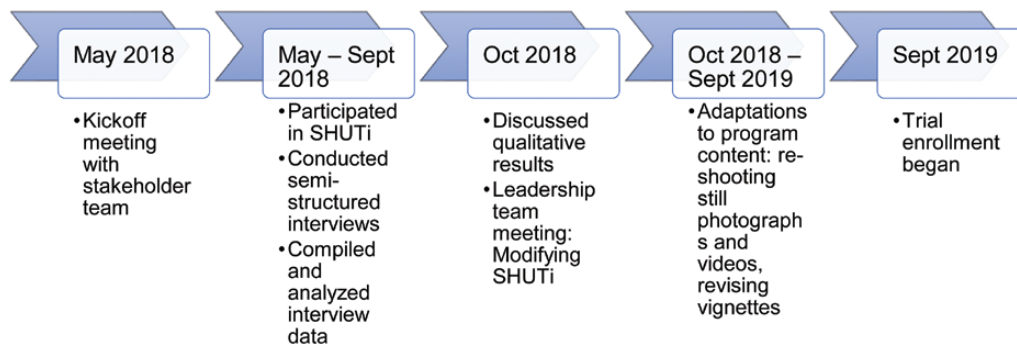


Figure 1 Program adaptation timeline

based on inputted symptoms, animations/illustrations to enhance comprehension, patient vignettes, and video-based explanations from experts.

- At the start of each session, SHUTi automatically reviewed the participant’s sleep diary data from the prior week, then tailored intervention recommendations and content delivery for that session based upon their baseline sleep, treatment adherence, and sleep progress.

We conducted modified usability testing utilizing a retrospective interview method with all stakeholders. First, all stakeholders were given directions on how to login and use the SHUTi program. They were instructed to consider both program-level and context-level factors pertinent to engaging Black women with insomnia in an online treatment program. To facilitate low-burden, sequential, and open-ended feedback from stakeholders for each of the program’s six sessions, as well as on the entirety of the SHUTi program, stakeholders were contacted after each session by one of two study interviewers, both doctoral-level researchers with qualitative methodology expertise. Phone interviews lasting 20–30 min followed a semi-structured guide developed by the study investigators. Interviews were recorded, transcribed, and systematically analyzed through a multi-stage iterative approach borrowing from thematic content analysis [49]. We took an iterative team-based approach to codebook development, which included deductive and inductive dimensions. The preliminary codebook was informed by the interview guide, with main domains from the interview guide serving as the initial prefigured/a priori codes. The initial codebook was revised and adjusted based on the review of all of transcripts for each specific session, and initial testing and discussion through an interactive group coding process. An individual codebook was then created for the interviews of each session of the program, for a total of six codebooks. This was done to better facilitate analysis examining within- and across-session feedback; however, codes remained consistent across all session codebooks. These final comprehensive codebooks were used to code all transcripts. The team used NVIVO (QSR International) in the coding and analysis process. Through team debriefings after coding was complete, the team identified concepts that aligned and echoed Kreuter *et al.*’s [37] Common Strategies for Enhancing Cultural Appropriateness. This then served as a guiding theoretical framework for organization of the code summaries and analysis.

Codes were reorganized along the main domains of the framework. As the *linguistic* (English is the primary language of the target group) and *constituent-involving* (our

stakeholder team was designed to draw from the experiences of Black women seeking care for insomnia) strategies were accomplished, the *peripheral*, *evidential*, and *sociocultural* strategies served as the guiding framework for the analysis. Through prolonged engagement with the data, code summaries, and team discussions, the team identified key themes pertinent to peripheral, evidential, and sociocultural strategies for cultural adaptation. These themes were used to develop adaptation recommendations. As data collection and analysis were iterative team-based processes, this allowed the team to examine, reflect upon, and discuss each session’s data as it was collected and transcribed to discuss any potential gaps or areas requiring additional exploration in subsequent session interviews. Considering these aspects of the research design and the consistency in feedback across stakeholder types, the team determined that both code and meaning saturation were met [50].

One summary was prepared that contained each stakeholder’s session-by-session recommendations, and a second summary highlighted the themes evident across the group’s overall experience with the program, including specific feedback on program reliability and engagement. For each of the six SHUTi sessions, before data were analyzed, we made the decision that at least 7 of the 9 stakeholders needed to be interviewed following each session. Both analytic summaries were shared with the stakeholder team prior to a follow-up meeting that occurred in October 2018. During this meeting, the group reviewed the analytic summary documents. Stakeholders were first asked to provide program-level (across sessions) recommendations addressing enhancement of cultural appropriateness, followed by a session-specific discussion to note any specific areas where modifications were necessary. Stakeholder team meetings were conducted to allow for open discussion and interaction regarding how to best address any limitations or concerns related to SHUTi. In these meetings, efforts were made to ensure equal power dynamics; for example, all stakeholders were addressed on a first name basis, rather than the use of professional titles (e.g. Doctor). The final goal was to gain a group consensus on potential changes to implement, where consensus was defined *a priori* as at least 7 of the 9 stakeholders agreeing on a modification suggestion.

While we acknowledge that some qualitative researchers prefer to rely on inter-rater reliability (IRR) or inter-coder reliability (ICR), it was not an appropriate measure for this context [51]. Coding is an interpretive act that requires awareness of context, reflexivity, and a deep understanding of qualitative assumptions in research. We drew on a collaborative approach

to codebook development and coding through the inclusion of interdisciplinary voices and team discussions that brought diverse viewpoints and expertise to the process. We prioritized team meetings to discuss codebook development, code application, and data interpretation to create collaborative and engaged exploration of the data. Through these meetings, we gained a more comprehensive understanding of the codes, text, and emergent ideas. Limiting the quality assessment of the coding process in a thematic analysis to IRR/ICR does a disservice to the richness and nuance necessary for an in-depth exploration of meaning. Further information about our data collection and analysis process can be seen in the Consolidated criteria for reporting qualitative research (COREQ) checklist in [Supplementary Appendix A \[52\]](#).

Results

A total of 50 stakeholder interviews were completed across the six SHUTi sessions, with at least eight stakeholders completing an interview for each session. Overall, stakeholders identified two overarching themes. First, they critiqued the limited African American representation in the program. Second, they noted the lack of diversity in the environments and lifestyles of the patient vignettes. Respondents focused on the critical importance of incorporating more Black women and men in the patient and provider examples, as well as diversifying the experiences of the individuals portrayed in the program content to include examples that would be viewed as more relevant for Black women. [Table 1](#) shows a summary of the domains where tailoring was recommended, along with the SHUTi modifications that resulted.

Within the *peripheral* domain, stakeholder interviews highlighted the importance of and preference for race-concordant visual content. They noted the importance of having more Black women and men in the patient vignettes, expert videos, and instructional videos (e.g. for relaxation practice). Regarding the content of the vignettes, there was an emphasis on having the storylines better reflect the lives of the target population, such as their home and/or work environments. Examples of team member comments were:

“we all like to see ourselves depicted in those stories and our different ethnicities depicted and our lifestyles”

“you have White male experts...I would rather have, and it’s a good modeling I think, to have well-educated Black women, expert[s] in sleep, give that talk”

“just knowing there’s people out there like me”

Within the *evidential* domain, stakeholder interviews indicated the need for specifying when presented information was salient for the African American community, such as the unique precipitants of insomnia in Black women. Stakeholders advised that research be shared on how this specific community is affected by insomnia. Exemplar quotes included:

“there isn’t any mention of race or racism, at all”

Within the *sociocultural* domain, stakeholder interviews underscored the benefit of didactic content that explored the cultural and social contexts in which insomnia occurs for Black women. Content-focused suggestions included risk

factors/issues that may be more pertinent to Black women, such as socioeconomic stress (e.g. housing instability), working jobs with inconsistent schedules, childcare and/or elder care responsibilities in a multi-generational home, environmental challenges to sleep (e.g. loud neighbors), and use of over-the-counter aids for sleep. [Figure 2](#) shows an example of a modification to standard SHUTi content related to neighborhood noise. Stakeholders emphasized the importance of affirming the experiences of Black women, indicating the value of positive reinforcement as they endeavored to make changes to their sleep health. It was advised that the environments of the patient vignettes be diversified to incorporate these issues within their storylines. Exemplar quotes include:

“if what’s keeping you up is your neighbor’s barking dog, what can you do?”

“more likely to have extended family under the same roof and not have total control over their environment...it might be more chaotic in another room”

“SHUTi needs to acknowledge and affirm Black women’s experience in this section to be more credible and supportive”

Intervention adaptation process

Feedback from the follow-up stakeholder meeting was collected. Then, two study investigators (LMR and ESZ) reviewed content from the standard SHUTi program and identified opportunities where content could be adapted to reflect the stakeholder recommendations. Eligible components included patient vignettes, expert videos, and didactic content. Over the course of 5 months, revisions were made to the intervention content by these two study investigators, focused on being responsive to all of the stakeholder comments. For example, we re-wrote the storylines of the patient vignettes in SHUTi to better align with the potential life circumstances of a Black woman. During this process, the stakeholder team was asked via email to provide their feedback on the new storylines, including selecting the names for the characters, as well as the specific actors/actresses who would represent those characters in the videos and still photographs. [Figure 3](#) shows an image from a video in the standard SHUTi program and the adapted version from the tailored program. Additionally, age, marital status, employment status, and health comorbidities of the patient vignettes were all varied to reflect the trial sampling frame. Also, two Black, female sleep physicians were engaged with the project and filmed giving expert advice on sleep during the intervention. Prior to implementing the proposed SHUTi modifications, additional study staff with expertise working with Black study participants reviewed the materials and provided feedback on the suitability of the program modifications for engaging Black women in the intervention. Based on their comments, we made minor changes to the visual layout and presentation of the program elements.

Discussion

Technology has the potential to be “the great equalizer” [\[53\]](#) for important health and information disparities. The development of Internet-delivered programs which provide gold standard insomnia therapy has been revolutionary: they provide convenient and cost-effective access to care that is

Table 1 Key stakeholder themes and exemplar quotes regarding SHUTi engagement for black women by domain and subsequent modifications

Domains from Kreuter <i>et al.</i> 's Common Strategies for Enhancing Cultural Appropriateness, Exemplar quotes, and SHUTi modifications	
Peripheral domain	Evidential domain
Themes	Themes
SHUTi modifications	SHUTi modifications
Sociocultural domain	
Themes	Themes
SHUTi modifications	SHUTi modifications
<p>More Black subjects to be represented in vignettes (“<i>Just knowing there’s people out there like me, a lady of color</i>”)</p>	<p>Presenting research data specific to Black Americans</p>
<p>Update all vignette content (still images and videos) to Black men/women</p>	<p>Where available, add data to support that information provided was sourced from a study involving minorities</p>
<p>Diversifying surroundings in vignettes (“<i>nothing that made it easy for somebody to connect</i>”)</p>	<p>Share data demonstrating prevalence of insomnia in Black women and its health effects</p>
<p>Re-write content and new images reflecting varied home/work environments</p>	<p>Introduce additional insomnia precipitants that may be more common among Black women</p>
<p>Experts should be Black (“<i>you have White male experts, a Black woman could care less who he is</i>”)</p>	<p>Unique precipitants for insomnia in Black women (“<i>there is no recognition of racism</i>”)</p>
<p>Relaxation videos should involve Black women (“<i>whether we do deep breathing, to actually have a video of a Black woman doing this I think is gonna be important</i>”)</p>	<p>Black women demonstrating relaxation activities</p>
<p>Varied life circumstances of vignette patients that reflect the diversity of Black women (“<i>Black women from a spectrum of social economic groups and backgrounds and family structures</i>”)</p>	<p>Over-the-counter sleep medication use (“<i>Benadryl is a default sleep med for me</i>”)</p>
<p>Modify vignettes to reflect women across the lifespan, from varying economic strata and household backgrounds</p>	<p>Discuss commonly used over-the-counter medications for sleep</p>
<p>Environmental challenges more likely to be pertinent for a Black woman (“<i>if what’s keeping you up is your neighbor’s barking dog, what can you do?</i>”)</p>	<p>Explore strategies to manage environmental challenges more relevant for Black women</p>
<p>Managing sleep in lower SES conditions (“<i>what if there’s too much light in the room? You can use a blanket. Anybody, in any economic circumstance, can kind of do that</i>”)</p>	<p>Provide alternative strategies to implementing sleep hygiene recommendations</p>
<p>Adherence challenges for Black women (“<i>more likely to have extended family under the same roof and not have total control over their environment...it might be more chaotic</i>”)</p>	<p>Promote family engagement to support the patient; provide alternative stimulus control strategies</p>

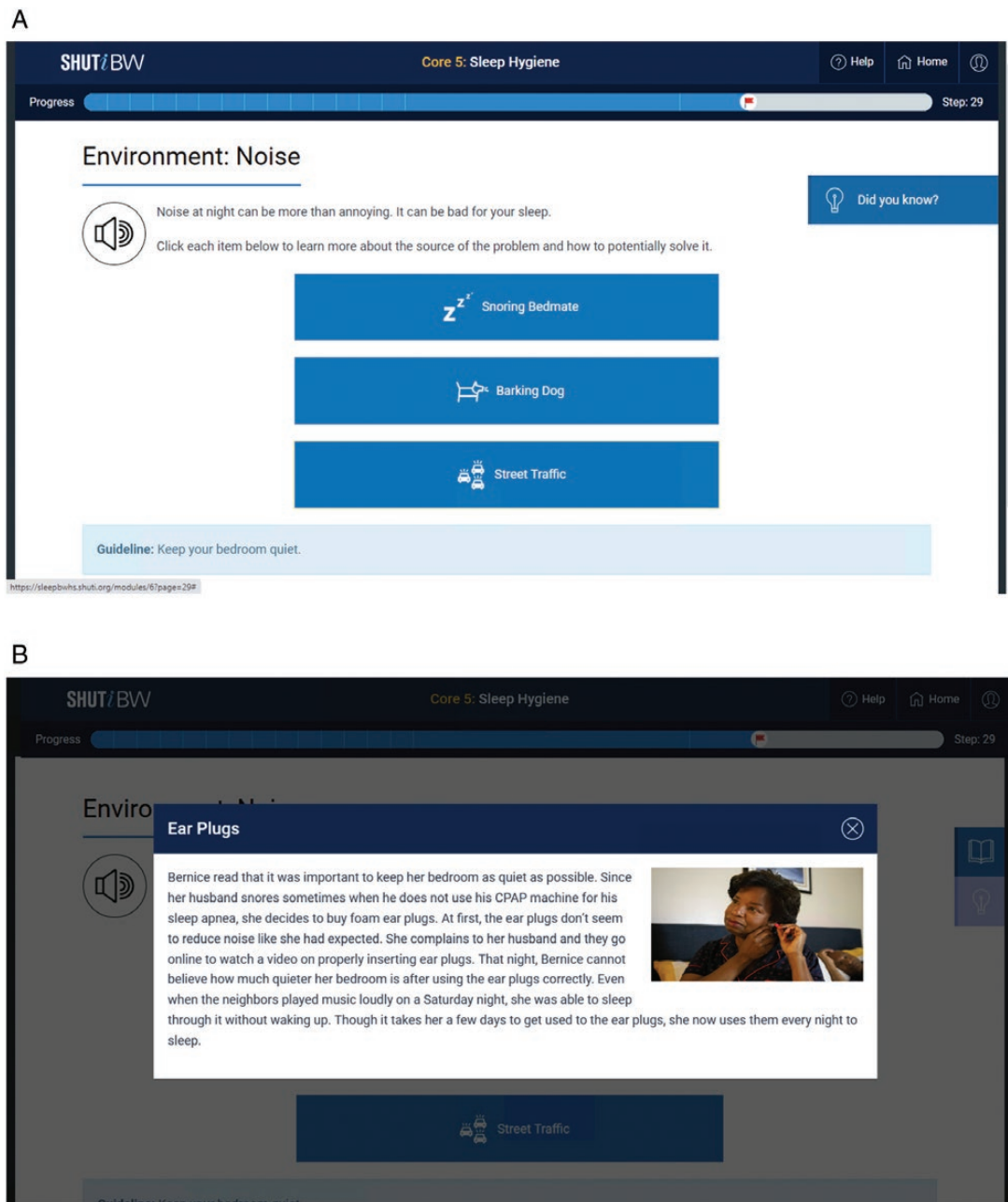


Figure 2 Example of the sociocultural content changes made from the standard SHUTi to the culturally tailored version. (a) Screenshot is from standard SHUTi, without discussion of how to cope with loud neighbors. (b) Screenshot is from culturally tailored SHUTi, including a separate section on coping with noise from neighbors

comparable in efficacy to in-person treatment at improving major sleep metrics [54, 55] and can improve downstream outcomes including anxiety and depression [56]. With increasing numbers of patients from diverse backgrounds seeking evidence-based treatment for their insomnia, developers of digital health interventions will increasingly need to consider the therapeutic importance of addressing differences between patient populations. In our study, stakeholders were enthusiastic about engaging in a project that spoke to this critical question, with clear recommendations for what they felt could be tailored in a “standard” program to enhance treatment engagement.

These findings beg the question of whether it is critical to *a priori* tailor a treatment protocol for varying patient

subpopulations. Have researchers been missing a key step in the implementation process as we advance from efficacy to effectiveness? A recently completed review suggested as much, stating that a “cultural appropriateness component” is necessary “in any intervention devised for reducing sleep health disparities” [57]. This assertion is concerning as there are extensive gaps in the literature in this field. In 2021, a systematic review of cultural adaptations of psychological/behavioral interventions for sleep disturbances revealed that less than 7% of randomized trials targeted an underserved or high-risk group (e.g. racial/ethnic minorities), with the majority focused on veteran health. The authors noted that up to that point, no previous trial had introduced “deep-level” modifications, which involve “incorporating sociocultural



Figure 3 Example of the visual changes made to the standard SHUTi compared with the culturally tailored version. (a) Standard SHUTi video, with family discussing the impact of aging on insomnia. (b) Culturally tailored SHUTi, with the same discussion topic with different actors/actresses and group activity

values...into the treatment paradigm,” into the CBT-I protocol for any cultural minority [58].

Our efforts were initially spurred by a gap between White and Black women with respect to the extent of their engagement with SHUTi in previous trials (e.g. number of website logins, program completion rates). Since then, other researchers have demonstrated that Black women are four times more likely than White women to discontinue CBT-I before receiving an adequate treatment dose [59]. Moving forward, it will be important to examine data on differential rates of recruitment or intervention engagement by important potential covariates, including race/ethnicity, sex/gender, and socioeconomic status, to determine whether additional subpopulations would benefit from a more tailored treatment program [60].

Researchers are advised to make as few *a priori* assumptions as possible about which groups may or may not be easier to recruit/engage. For example, data from a trial of another Internet-delivered CBT-I program suggested that there may not be racial differences in terms of program engagement [61]. While this is in contrast to our preliminary data, these findings may be explained by the younger mean age of that study population and potential generational gaps in comfort with technology use and telemedicine in general. With comfort with technology varying across generations, potentially impacting learning preferences [62], it may be important to consider tailoring treatment to different age groups. Accordingly, there have been recent efforts to tailor SHUTi to older adults [63].

To achieve the ability to detect between-group differences in engagement, we must do a far better job of first conducting research in more socio-demographically diverse populations. Prior trials of CBT-I have been so homogenous that recent reviews ignore racial/ethnic differences in study outcomes because of a paucity of data [64–66]. Our study is among the first digital health trials to focus on insomnia in a minority population, and is unique in that recruitment was directly from a well-characterized longstanding cohort, Black women. This may help to explain why program completion rates in this minority population (63%) were comparable to rates seen in previous SHUTi trials conducted in majority non-Hispanic White populations [40]. Even in this motivated cohort of research participants, we saw a 15% increase in program completion when a tailored intervention was provided. Understanding what drove this difference is of the utmost importance to expanding efficacious treatment among underserved patients. For example, identifying key sociodemographic, psychological, medical, or sleep-specific characteristics of women who completed the culturally tailored version of SHUTi but would not have completed the standard version would provide insight into this difference. Next, it would be intriguing to evaluate whether a multi-cultural version of SHUTi, with vignettes and expert videos of racially/ethnically diverse patients, families, and experts, would be as effective as our tailored program in terms of engaging the same (Black women) or different (e.g. Hispanic men, Asian women) minority patient populations. Finally, an unanswered question for digital health programs like SHUTi is whether the use of personalized medicine could be a better approach. Indeed, future iterations of SHUTi may incorporate a broad library of visual and didactic content, with specific materials automatically shared with patients based on an algorithm that considers certain factors that may influence treatment engagement (e.g. race/ethnicity, age, gender identity, sexual orientation, comfort with technology).

The COVID-19 pandemic has resulted in the rapid adoption of telehealth at the institutional level and increasing comfort with technology in the context of healthcare for patients [67, 68]. Prominent health disparities in access to insomnia treatment can potentially be addressed with the use of Internet-delivered programs. To truly transform sleep health at the population level, it is imperative that we learn what predicts treatment engagement and use this vital information to tailor automated interventions “on the fly.” As adapted program content is developed, it is essential to include the voices of stakeholders from the beginning of the process. We hope that the approach described herein will serve as an adaptable model to facilitate this critical aspect in future work.

Supplementary data

Supplementary material is available at *Translational Behavioral Medicine* online.

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Conflict of Interest

Dr. Zhou has received research funding from Jazz Pharmaceuticals and Harmony Biosciences, and consulting fees from MindUP and Samsung. Dr. Ritterband has received personal fees from Pear Therapeutics and Mahana Therapeutics, is a member of the Board of Directors and owns equity in BeHealth Solutions, and has a patent for Sleep Healthy Using the Internet with royalties paid from Pear Therapeutics. Dr. Bethea has received personal fees from George Washington University.

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Informed Consent

Informed consent was obtained from all individual participants included in the study.

Transparency Statements

This study was not formally registered. The analysis plan was not formally pre-registered. De-identified data, analytic code, and materials from this study are not available in a public archive. De-identified data, analytic code, and materials from this study will be made available (as allowable according to institutional IRB standards) by emailing the corresponding author.

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