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"Better Sleep Means I'm Better Able to Provide Care": Caregivers' Perceived Impacts of an Internet-Delivered Insomnia Intervention

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Abstract

Introduction: Family caregivers frequently experience sleep challenges that impact their own health and ability to provide care for a care recipient (i.e., the person a caregiver supports). Cognitive-behavioral therapy for insomnia (CBT-I) effectively treats insomnia, but there is limited evidence regarding caregivers' perceived impacts of this intervention. The current study evaluated caregivers' experiences using Sleep Healthy Using The Internet (SHUTi), an Internet-delivered CBT-I intervention.

Method: The sample comprised caregivers with insomnia who supported care recipients requiring medium- or high-intensity care for any condition, including Alzheimer's disease/dementia (21%), cancer (11%), or a mobility problem (11%). Participating caregivers who used SHUTi (n = 82; age M = 53.20, 85% female, 59% lived with the care recipient) provided open-ended feedback about their experience. Responses were analyzed using a rapid content analysis approach.

Results: Responses revealed that caregivers perceived benefits of SHUTi to their *functioning* and their *understanding of sleep*. Caregivers described how the intervention improved their overall daytime abilities, mood, and caregiving capacity. They also shared how the intervention helped them prioritize sleep and self-care, gave them insight into their sleep, and increased their knowledge of healthy sleep.

Discussion: Caregivers reported wide-ranging benefits from CBT-I beyond improved sleep. Despite the untailored nature of this intervention, several caregivers described positive impacts on their caregiving capabilities and outlook, resulting from the program helping them to improve

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their sleep and self-care more broadly. These results suggest that framing caregiver-focused health interventions as important to both caregivers and care recipients may increase caregivers' uptake of such resources.

Keywords

Cognitive-behavioral therapy for insomnia; Caregivers; Internet intervention; Self-care; Care partner; Sleep initiation and maintenance disorders; Qualitative research

Introduction

There are more than 63 million caregivers in the United States (US) who provide care for a family member or friend (i.e., care recipient)[1]. Caregivers play a critical role in maintaining the health of their care recipients, performing personal care, medical, household, and social tasks [53], [55] for a reported average of about 27 h per week [1]. While caregivers often report benefits from their role [41], [48], caregiving can yield negative impacts across social functioning, mental health, physical health, and financial wellbeing [7], [29], [50], [64]. These negative consequences are exacerbated among caregivers who provide more hours of care with less outside help [1]. Given that adverse health and well-being among caregivers has downstream health consequences for care recipients [4], [65], supporting caregivers is a critically important health initiative.

Sleep challenges have been identified as a common health consequence of caregiving across different caregiving populations. Caregivers of individuals with dementia report sleep disruptions from managing the care recipients' nighttime dementia behaviors [12], [27], [30]. When compared to non-caregivers, caregivers of children with medical needs report shorter sleep duration, worse sleep efficiency, and greater time waking after sleep onset [80] from co-sleeping, overnight caregiving, hypervigilance, and care recipient sleep disruptions [20], [52], [54], [73]. In addition, several studies have reported that caregivers build their sleep routine around a care recipient, demonstrated through later bedtimes than care recipients [17], [47] and earlier waking times [14], [16], [47]. Furthermore, caregivers also endorse higher levels than the general population of comorbid conditions that are themselves associated with sleep difficulties, including depression and anxiety [15], [18], [26], [60].

Given these sleep impacts of caregiving, it is perhaps unsurprising that caregivers are at greater risk for insomnia relative to age-matched non-caregivers [13], [27], [51]. Insomnia presents as challenges with falling asleep at bedtime, waking up in the middle of the night with difficulty going back to sleep, and/or waking up early in the morning without being able to fall back to sleep [2], [3]. People with insomnia can experience physical discomfort, lower energy, and increased emotional reactivity, all of which can interfere with social relationships and quality of life [42], [45], [51], [75]. Long-term consequences of insomnia include a higher risk for anxiety, depression, high blood pressure, migraines, and heart conditions [6], [11], [16]. In addition to the personal health impacts of insomnia that caregivers may experience, poor caregiver sleep also contributes to increased care recipients' health care expenditures and a greater risk of nursing home placement [4],

[24]. Improvement of caregivers' sleep is, therefore, an important target for interventions to support caregivers and care recipients.

While evidence suggests that SHUTi may be an accessible and effective way to address the common problem of poor sleep among caregivers, caregivers often underutilize available supportive care interventions [46], [76], [81]. Understanding what program outcomes mattered most to caregivers themselves may help frame SHUTi in a more appealing way to encourage uptake among caregivers while also capturing any unanticipated intervention effects. Therefore, this study reports secondary findings from caregivers' open-ended responses following their experience with SHUTi regarding how completing the intervention influenced their functioning, health, and sleep.

METHODS

This manuscript reports secondary qualitative findings from the SHUTi-CARE (Caregiver Acceptability REsearch) study, a single-group trial of SHUTi among family caregivers. The trial (ClinicalTrials.gov NCT04986904) and protocol [68] were pre-registered. This manuscript adheres to the guidelines outlined in the COREQ checklist [78] (see Supplementary Table 1). Study materials are publicly available at [https://bit.ly/SHUTiCARE-project], and data are available by data use agreement. Complete details about the trial methods, intervention, and participants have been previously reported in the published trial protocol and primary outcomes reports [67–69]; key details are briefly summarized here.

Participants

Participants were recruited from across the US via the internet from January to December 2022. Following the National Alliance for Caregiving (NAC) definition, a caregiver was defined as someone who delivers unpaid care to an adult relative (or family-like individual) and/or to a child due to the child's medical, behavioral, or developmental condition or disability [1]. Caregivers were eligible for the trial if they (1) provided medium- or high-intensity care based on the NAC Level of Care Index ([1]; i.e., were "higher-intensity caregivers" due to spending many hours per week supporting multiple care tasks [68]), (2) expected to provide this level of care for at least three additional months, (3) were aged 18 or older, (4) reported clinically significant insomnia symptoms on the Insomnia Severity Index [8], [57], (5) had regular access to the Internet, (6) were willing to receive study emails, (7) spoke and read English, and (8) were US residents. Caregivers were excluded if they reported (1) an irregular sleep schedule (e.g., paid shift work), (2) receiving current behavioral or psychological treatment for insomnia, (3) severe challenges with using a computer, or (4) certain medical or psychiatric contraindications (e.g., restless leg syndrome, mania).

For this analysis, only participants who had experience with SHUTi by using the program (i.e., completed at least the first SHUTi Core) were included (n = 82, of whom 78 provided at least one coded quotation at post-assessment); participating caregivers who did not complete any Cores (n = 18) were not asked about the program and therefore cannot be included. On average, included caregivers were middle-aged (M = 53.2 years), and

most were female (85%), white (79%), and non-Hispanic (95%), with at least a college degree (65%). One in five reported an annual household income under $30,000 USD. These caregivers reported providing care for about 5 years on average, with over one-third providing care to two or more care recipients. Caregivers provided care for primary care recipients with a variety of conditions, including Alzheimer's disease or dementia (21%), cancer (11%), or a mobility problem (11%). See Table 1 for further sample details. Most caregivers who used SHUTi completed it per protocol (i.e., through Core 4; $n = 60$ [73.2%]) and 48 (58.5%) completed all six Cores. Only five caregivers (6.1%) stopped after completing the first Core (for complete CONSORT chart:[67]).

Procedures

Procedures were approved by the University of Virginia Institutional Review Board (IRB) for Health Sciences Research (HSR210255) and the University of Pittsburgh Office of Research Protections IRB (STUDY21080076). Interested individuals completed an online pre-screening form. The identities of pre-eligible individuals based on the pre-screening form were verified using TLOxp (TransUnion), a web-based people search service, to ensure participant authenticity [31]. The research coordinator conducted a phone eligibility screening with verified individuals to confirm their eligibility. At the end of this call, individuals who were confirmed eligible and wanted to enroll provided informed consent via DocuSign. Participants then completed an online baseline assessment and subsequently received access to SHUTi for 9 weeks. At the end of this intervention period, participants completed the post-assessment. Participants were compensated $40 USD after completing each assessment. Online assessments were completed via a HIPAA-compliant web-based survey tool, Qualtrics Highly Sensitive Data (Qualtrics, Provo, UT).

Intervention

A full description of the SHUTi intervention has been published [77], with a summary and other details in the published study protocol [68]. In brief, SHUTi is a fully automated Internet-delivered insomnia program that is accessible via computer, tablet, or smartphone through a password protected website. There are six sequential "Cores" that deliver the primary treatment mechanisms of CBT-I: basic sleep education, sleep restriction, stimulus control, cognitive restructuring, sleep hygiene, and relapse prevention. Users gain access to the next Core one week following the completion of the previous Core. The program employs quizzes, videos, games, and automated reminder emails to engage users. It provides tailored recommendations based on user inputted data (e.g., from Sleep Diaries). Technical assistance is available from study staff, but no clinical guidance is provided. There is no caregiver-specific content or tailoring.

Measures

Participants who completed at least the first SHUTi Core responded to open-ended prompts at post-assessment about aspects of the program about which they were satisfied or dissatisfied and their experience with SHUTi as a caregiver [67]. See Supplemental Table 2 for full open-ended prompts.

Data Analysis

The > 600 open-ended responses shared by caregivers who used SHUTi were analyzed using a rapid content analysis approach with matrix analysis methods [5], [35]. Two independent reviewers, KS, KP, MM, JG, HD deductively coded each response according to an a priori codebook. Discrepancies were resolved by the consensus of a third coder or the full coding team. Quotes were then grouped according to those expressing satisfaction (or a treatment benefit) versus dissatisfaction (or a treatment difficulty) to facilitate synthesizing themes across similar quotes. All qualitative data coding and analysis for the primary qualitative outcomes analysis and this secondary analysis were completed together. Themes related to the primary qualitative study aim on SHUTi usability and appropriateness for caregivers have been previously published [67]; this paper reports major themes related to program impact that were outside the scope of the primary analysis.

RESULTS

See Table 2 for a listing of themes (in bold below) and codes (in italics below). Quotations are labeled with an identifying number, the primary care recipients' condition requiring care, and the last Core completed by the participant. A summary of all qualitative themes was emailed to caregivers with a brief survey for synthesized member checking [10] to assess the degree to which results aligned with caregivers' experiences. Most responding caregivers endorsed that the summary matched their experience and did not recommend changes [67]. Member-checking responses with contrasting or clarifying perspectives are included in the results below.

Impact on Caregivers' Functioning

Several codes emerged related to the impacts caregivers experienced on their daily activities, mood, and caregiving experience during and following their SHUTi participation. Most caregivers expressed that the *program was helpful* both in general and more specifically for improving their sleep. One caregiver noted changes following the program including, "I have slept 5–6 h straight with few early morning wake ups" [Caregiver (Cg)1, Alzheimer's disease/dementia, Core 6], and another commented more generally that SHUTi "helped to improve my sleep quality" [Cg2, cancer, Core 1]. As found in the primary qualitative analysis [83], the realities of caregiving sometimes interfered with caregivers' ability to follow and fully benefit from the program. As one caregiver remarked about following the program recommendations, "it didn't always work out due to my caregiving responsibilities, but my sleep isn't as chaotic as it was before I started this program" [Cg3, other condition, Core 6].

Caregivers remarked more specifically on the positive *daytime performance impacts* of getting better sleep as a result of working through the program, sharing how "better sleeping helps make a better day" [Cg4, other condition, Core 6]. One caregiver described how SHUTi "helped me improve my quality of sleep, which helped me focus on daily activities and be more energetic and alert" [Cg5, Parkinson's disease, Core 6]. Other caregivers also noted increased alertness, with one caregiver sharing they felt "more helpful and awake during the day" [Cg6, cancer, Core 6].

Caregivers described specific *mood impacts* from using the program as well. One caregiver wrote, “when I stuck to SHUTi I felt more relaxed and restored” [Cg7, mobility problem, Core 6], and another caregiver described how their improved sleep resulted in feeling “less cranky” [Cg8, mobility problem, Core 6]. One caregiver shared how her experience with SHUTi influenced her mood specifically as it related to her caregiving role: “I do not feel any type of anger, resentment, or frustration with the situation any longer. I am much more friendly with [my care recipient] as well as being more patient, personable” [Cg9, cancer, Core 6]. While many caregivers experienced positive impacts on their mood, one caregiver did note a negative mood impact: “I did try the sleep window for two or three nights…I felt so awful that I was short-tempered with [the care recipient] and had little patience when he [was] confused or contrary” [Cg10, Alzheimer’s/dementia, Core 6]. Findings suggest caregivers may experience short-term negative mood influences from changes to their sleep behaviors and increased sleepiness but substantial long-term benefits to mood if they can persist with the program.

These findings regarding the balance between short-term challenges versus substantial long-term benefits were mirrored in caregivers’ comments about how SHUTi influenced their ability and motivation to provide care. Many participants described positive *caregiving impacts*, namely, that “getting a better night’s sleep allows me to perform caregiver duties (and other tasks) better” [Cg11, mobility problem, Core 2]. One caregiver described a profound change in her caregiving from before to after her use of SHUTi: “Before SHUTi, I was genuinely operating on ‘one leg.’ I was SO CLOSE to throwing a temper tantrum and just quit trying to help my [care recipient]… Now, I feel motivated to help…It doesn’t feel like ‘work’ to me any longer. I ENJOY going there each day” [Cg9, cancer, Core 6]. Another caregiver indicated that the practical guidance to improve sleep in SHUTi “taught me the best way and time to get sleep for me and feel better and more able to help my loved one” [Cg12, back problems, Core 6]. This concept was reinforced through member checking, with one caregiver wishing to emphasize “how important sleep is to health and well being. Can’t be a good caretaker [if] you aren’t taking care of yourself” [Cg13, other condition, Core 6]. While most caregiving impacts were positive, a few caregivers also noted negative impacts from completing the program, particularly regarding the initial sleepiness induced by sleep restriction. One caregiver described particular challenges enduring the sleep restriction technique, saying that “it can be brutal to caretake and stay awake” [Cg14, Alzheimer’s/dementia, Core 6]. Thus, while caregivers generally described long-term benefits of improved sleep on their caregiving experience and capabilities, some did experience short-term hardship from the behavioral strategies.

Better Understanding of Sleep

In addition to improving daily functioning, caregivers remarked on how their understanding of, and appreciation for, sleep changed as a result of using SHUTi. Caregivers described feeling more knowledgeable about insomnia and how to promote healthy sleep after using the program (*learning about healthy sleep*). Caregivers appreciated learning about the “how’s and why’s of sleep” [Cg12, back problems, Core 6], such as how their habits and sleep environment can affect their sleep. Several caregivers specifically wrote about benefitting from learning how creating a routine can improve sleep quality. One caregiver

shared how SHUTi “helped me see sleep patterns [and] educated me on potential problems [with] my sleep habits” [Cg15, mental illness, Core 4]. Not all caregivers found the sleep education useful; one caregiver shared “It’s educational but not really effective in the real world” [Cg16, mobility problem, Core 2]. Overall, most caregivers reported that learning about “the science behind sleep” [Cg17, cancer, Core 6] was important to their ability to identify and address their sleep problems.

More specifically, caregivers appreciated gaining more *insight into their own sleep* needs and habits. They described benefits from becoming more aware of their sleep patterns through completing sleep diaries. One caregiver stated, “Sleep diaries are really interesting and useful. They’ve made me much more aware of how I use my sleep time” [Cg14, Alzheimer’s/dementia, Core 2]. This sentiment was shared by another caregiver, who remarked, “The program made me look at my sleep habits and assisted me with a better understanding of how I can help myself lead a healthier sleep life” [Cg18, other condition, Core 6]. Similarly, another caregiver was able to “analyze what’s affecting my sleep” [Cg19, autism spectrum disorder, Core 6] by learning about healthy sleep from SHUTi Cores. Another caregiver reiterated the importance of understanding the influence of their behaviors on their sleep during the member checking process, sharing “I am VERY aware of what I do throughout the day to maintain healthy sleep” [Cg20, other condition, Core 6].

Another key learning that caregivers identified from the program was that they were *not alone in insomnia.* They expressed relief from learning “that it wasn’t only me not sleeping well” [Cg9, cancer, Core 6]. One caregiver commented that SHUTi “normalized some of the issues I was having and convinced me to look at things from a different perspective” [Cg21, Alzheimer’s/dementia, Core 6]. Another caregiver particularly appreciated “the ability to read others’ stories who have experienced insomnia” [Cg22, brain damage or injury, Core 6] in the SHUTi program, as this helped her feel less alone with her own sleep challenges.

Lastly, several caregivers discussed coming to appreciate the critical role that sleep plays in their daily lives and the benefit of *prioritizing sleep and self-care*. One caregiver shared that SHUTi “helped me make my sleeping habits a priority, which spills over positively into every [other] area of my life” [Cg6, developmental or intellectual disorder or disability, Core 6]. Similarly, a caregiver conveyed how SHUTi helped her balance tasks that supported her self-care, sharing that “it helped me figure out what is best for me and how to work with caregiving on top of managing to get my own rest” [Cg12, back problems, Core 6]. Another caregiver described how SHUTi “helped me as a caregiver by allowing [me] to take time out for myself instead of always meeting the needs of my [care recipient]” [Cg22, brain damage or injury, Core 6]. Even those caregivers whose responsibilities made adhering to the SHUTi program more challenging came away with a better appreciation for self-care, with one such caregiver noting that her “responsibilities made it more difficult to follow the recommendations, but SHUTi also showed me the importance of taking care of my needs” [Cg23, other condition, Core 5]. Similarly, another caregiver reported, “In order to be an effective caregiver, I need to care for myself” [Cg5, Parkinson’s disease, Core 6]. These findings are particularly notable given there is no content in SHUTi expressly about caregiving or self-care.

DISCUSSION

Caregivers providing significant, time-intensive support to ill family members and friends described positive impacts of an Internet-delivered CBT-I program across multiple domains of their lives. Moreover, they detailed how these benefits to their daytime performance, mood, and overall appreciation of sleep ultimately supported their ability to participate in their loved one's care. Caregivers' experiences with the program were not universally positive, with some caregivers expressing challenges related to sleepiness and fatigue induced from the behavioral CBT-I strategies. However, the overarching themes from caregivers' responses suggest that, if short-term challenges can be endured, caregivers' long-term benefits from improved sleep can be significant. Findings are notable given the high-intensity caregiving sample that was otherwise diverse with respect to disease context, living arrangements, relationship to the care recipient, and other caregiving contextual factors. While the benefits of SHUTi for caregivers were previously demonstrated through validated surveys and sleep diary metrics [69], these qualitative findings extend this evidence to capture the positive effects that caregivers perceived as most notable from their experience with the program.

Caregivers completing one or more SHUTi Cores described multiple ways that the program influenced their lives, with benefits extending beyond their sleep to improved mood and daytime functioning. The wide-ranging benefits of CBT-I have been endorsed by other populations, as well. For example, a pilot study of a CBT sleep intervention for adolescents with ADHD found that participants described feeling more ownership over their sleep and gaining insight into their sleep during their participation [39]. Similarly, a smartphone-based CBT intervention for individuals with psychosis identified benefits beyond sleep following the intervention, including improved daytime functioning, mood, well-being, and social interactions [75]. The current study aligns with this existing evidence, while providing specific reports from a caregiver population with their own unique sleep, health, and well-being challenges. Given the high rates of depression and anxiety among caregivers [18], [21], [26], [61], [70], emphasizing these additional mental health benefits from CBT-I may increase its appeal to caregivers.

In addition to improving their health and well-being, many caregivers described an improvement in the quality of their interactions with their care recipient that resulted from getting better sleep after SHUTi. This finding fits with extensive research in the general population linking sleep quality and social relationships [9], [32]. Poor sleep has been associated with increased relational conflict [33], with evidence suggesting these social impacts are at least partially due to changes in affective and physiological reactions to social experiences [25], [34], [63]. Within the specific social relationship between care recipients and their caregivers, previous research has revealed a direct connection between a caregiver's sleep problems and relationship quality with their care recipient [45], [62]. This evidence is further substantiated by findings from the current study, with caregivers from varied caregiving contexts and relationships to the care recipients perceiving improved interactions with their care recipient after improving their sleep quality with SHUTi.

Despite there being no caregiving-specific content in SHUTi, caregivers who used the intervention reported that they felt better able to provide high-quality care as a result of their improved sleep, mood, and functioning. This particular intervention impact is noteworthy, given that caregiver perceptions of their ability to perform caregiving tasks have previously been associated with better care recipient outcomes. For example, in a study of a heart failure self-care intervention, patients had better self-care maintenance and management when their caregivers had higher confidence in their ability to help the patient perform self-care [79]. Similarly, when caregivers report feeling underprepared and have low confidence in their caregiving abilities, care recipients have higher rates of hospitalization and institutionalization [38], which are extremely costly to the families and the American healthcare system [40], [44], [49]. Caregivers' responses about the impact of SHUTi on their caregiving capabilities suggest that addressing caregiver health concerns like insomnia may be key to supporting caregivers' role performance. Evidence of downstream impacts from behavioral health interventions for caregivers to their care recipients, including potential cost savings from delayed institutionalization or reduced emergency room utilization, may be useful to encourage the broader implementation of supportive care efforts for caregivers within standard care.

Additionally, caregivers reported learning more about the importance of self-care and how to prioritize it. One caregiver noted during member checking, "I wish this was more widely available to others! Especially those who are caregivers as we are often forgotten about and rarely take care of ourselves" [Cg6, cancer, Core 6]. Previous research on caregivers' self-care has identified guilt about self-care competing with their caregiving responsibilities as a major barrier to caregivers' engagement in self-care [56], [71]. Primary analyses from this trial demonstrated that caregivers' guilt about self-care did not interfere with their engagement with the program, but in fact was associated with *better* program outcomes [69]. SHUTi includes didactics that emphasize the importance of following healthy sleep behaviors to one's overall physical and mental well-being. It is possible these teachings may have helped caregivers connect how caring for themselves ultimately benefits (and therefore, does not compete with) their caregiving priorities. Marketing caregiver-focused health interventions as benefitting not only caregivers themselves, but also their care recipients, may help increase caregivers' notably low uptake of such interventions [46], [76], [81].

While caregivers described many long-term benefits of the program, some also reported short-term challenges, a tension that is found widely across CBT-I studies. Caregivers described common complaints and challenges about sleepiness and fatigue. The sleep restriction behavioral component of CBT-I purposely and systematically induces sleep deprivation in order to re-establish proper sleeping dynamics and increase sleep efficiency [72]. Particularly during the first few weeks of implementing this strategy, undesirable cognitive (e.g., difficulty concentrating), mood (e.g., irritability), and physical symptoms (e.g., extreme sleepiness) have been frequently reported [23], [43], [74]. Some caregivers in this trial described how challenges from implementing this strategy and the resulting symptoms made completing the program difficult to impossible [67], with similar sentiments previously documented among non-caregivers [43]. While sleep restriction is known to be challenging, this therapeutic component is highly effective for treating insomnia [22]. It is worth emphasizing with caregivers and non-caregivers alike during CBT-I that the temporary

sleepiness induced from sleep restriction can be expected to pay off with significant sleep improvements in the long term while also providing counseling on how to better manage any undesirable symptoms in the meantime.

Limitations and Future Research

One important limitation of the current study was that the sample comprised more non-Hispanic white caregivers and was overall more highly educated relative to the general US caregiving population [1]. Lack of sample diversity is a frequent challenge in clinical trial research [36], [58], and a problem we attempted to reduce with diverse recruitment sources (i.e., research registries, web-based advertisement, and in-clinic advertisement, [68]), but findings should be considered with this constraint. Future research is needed to intentionally recruit more ethnically and educationally diverse caregiver samples to assess the robustness and generalizability of these findings. Furthermore, while our sample was predominantly female, this reflects the overrepresentation of women within the population of informal caregivers as well as the elevated prevalence of insomnia among women [17], [37], [59].

While our sample does not directly mirror the general caregiving population in terms of racial/ethnic background and education level, we were able to capture a wide range of caregiving experiences. Caregivers in the current study had varying caregiving durations, relationships with their care recipients, and care recipients with different ages and conditions. This enhances the generalizability of our findings across caregivers broadly; however, the limited sample size did not permit analyses by care-recipient condition, so nuanced differences of specific caregiver subgroups may be obscured. Lastly, this trial was limited by the single-group design; however, these findings provide a positive signal that a randomized controlled trial is warranted to more robustly quantify the benefits of CBT-I among caregivers. In addition, towards addressing the problem of low uptake of support interventions among caregivers [19], [28], direct study is warranted on whether caregivers may be more likely to try interventions that promote wide-ranging benefits for themselves and downstream benefits for their care recipients.

Conclusions

By improving their sleep, caregivers from diverse caregiving contexts reported wide-ranging downstream benefits to their daily functioning, mood, and social relationships following the use of a fully automated Internet insomnia intervention. Furthermore, several caregivers expressed that the program provided permission to focus on improving their own health, which ultimately led to positive impacts on their caregiving capabilities and outlook on caregiving—despite SHUTi containing no caregiving-specific content. Although short-term challenges from sleep restriction were noted, most caregivers expressed that following the CBT-I principles made a positive impact on their lives. Findings underscore the importance of making CBT-I more widely available to caregivers given the multiple positive impacts to caregivers themselves and to their care recipients indirectly. Framing caregiver-focused health interventions as beneficial to both caregivers themselves and their care recipients may encourage more caregivers to engage with these resources, as well as promote their implementation into standard care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Declarations & Competing Interests

KP, VG, JG, HD, MM, JK, and KS have no conflicts to report. Over the past 3 years, DB has served as a paid or unpaid consultant to Sleep Number, Idorsia, and Eisai. All consulting agreements have been for a total of less than $5000 per year from any single entity. Consulting has focused on insomnia, behavioral sleep treatments, and the measurement of sleep characteristics. DB is an author of the Pittsburgh Sleep Quality Index, Pittsburgh Sleep Quality Index Addendum for PTSD (PSQI-A), Brief Pittsburgh Sleep Quality Index (B-PSQI), Daytime Insomnia Symptoms Scale, Pittsburgh Sleep Diary, Insomnia Symptom Questionnaire, and RU_SATED (copyrights held by the University of Pittsburgh). These instruments have been licensed o commercial entities for fees. He is also co-author of the Consensus Sleep Diary (copyright held by Ryerson University), which is licensed to commercial entities for a fee. LR reports having equity ownership in BeHealth Solutions, LLC, the company that was originally established to make available digital health products, including Sleep Healthy Using the Internet (SHUTi), now licensed by Nox Health. LR is a paid consultant of Nox Health, which owns the IP of Somryst, a commercial PDT for insomnia based on the SHUTi program. These companies had no role in the preparation of this manuscript. The terms of these arrangements have been reviewed and approved by the University of Virginia in accordance with its policies.

Data Availability

De-identified quotations are available via data use agreement with the University of Virginia. Contact the corresponding author to initiate the contracting process. Code book, coding form, and materials used to conduct the study are available at https://bit.ly/SHUTiCARE-project.

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Table 1.

Sample Characteristics (N=82)

Caregiver Characteristic	N, %, unless specified
Age (*M* [SD])	53.20 (13.37)
Gender	
Female	70 (85.4)
Male	10 (12.2)
Other[1]	2 (2.4)
Race	
Asian	4 (4.9)
Black/African American	12 (14.6)
White	65 (79.3)
Other or Multiple	1 (1.2)
Ethnicity	
Hispanic/Latino/a	4 (4.9)
Not Hispanic/Latino/a	78 (95.1)
Household income	
<$30,000	17 (20.7)
$30,000 – 50,000	22 (26.8)
$50,000 – 75,000	14 (17.1)
$75,000 – 100,000	9 (11.0)
>$100,000	14 (17.1)
Prefer not to answer	6 (7.3)
Education	
High school degree/GED	9 (11.0)
Associate's degree/some college	20 (24.4)
Bachelor's degree	21 (25.6)
Some graduate education	6 (7.3)
Graduate degree	26 (31.7)
Health literacy[2]	
Quite a bit, A little	8 (9.8)
Extremely	74 (90.2)
Months providing care to CR (*M* [SD])[3]	64.27 (42.21)
11 or more years	13 (15.9)
Total number of care recipients	
1	51 (62.2)
2	28 (34.2)
3	2 (2.4)
4 or more	1 (1.2)

Caregiver Characteristic	**N, %, unless specified**
Care provided to	
Adult(s) only	70 (85.4)
Child(ren) only	4 (4.9)
Adult(s) and child(ren)	8 (9.8)
Caregiving intensity score (*M* [SD])	8.52 (2.54)
Medium intensity (score = 5)	11 (13.4)
High intensity (score>5)	71 (86.6)
Proximity to CR	
Bed partners	19 (23.2)
Live together, sleep separately	29 (35.4)
Other living situation	34 (41.5)
Primary Care Recipient (CR) Characteristic	**N, %, unless specified**
Age[4] (*M*[SD])	65.38 (24.28)
90 and older	6 (7.3)
Relationship with caregiver	
Spouse, partner	21 (25.6)
Parent, parent-in-law	36 (43.9)
Son, daughter	11 (13.4)
Other	13 (17.1)
Primary condition requiring care	
Alzheimer's disease/dementia	17 (20.7)
Autism spectrum disorder	4 (4.9)
Back problems	3 (3.7)
Brain damage/injury	3 (3.7)
Cancer	9 (11.0)
Developmental/intellectual disorder	3 (3.7)
Feeble, unsteady, falling	2 (2.4)
Lung disease, emphysema, Chronic obstructive pulmonary disease (COPD)	3 (3.7)
Mental/emotional illness	2 (2.4)
Mobility problem	9 (11.0)
Old age	7 (8.5)
Parkinson's disease	4 (4.9)
Stroke	4 (4.9)
Other	12 (14.6)

[1] Inclusive of transgender, genderqueer, other, prefer not to say.

[2] Responses refer to the participant's level of confidence filling out medical forms.

[3] Care duration was assessed up to 11 years (last option = ("11 or more years") – recoded to 11 years for computing *M*, SD.

[4] CR age was assessed up to 90 (last option = ("90 or older") – recoded to 90 years for computing, *M*, SD.

Table 2:

Themes and Codes Overview

Theme	Code (Totals: Number of caregivers endorsing [N_c]; Number of total quotes [N_t])
Impact on Caregiver's Functioning: How the SHUTi program impacted caregiver participants' functioning	Program Helpful (N_c=52; N_t=111)
	Daytime Performance Impacts (N_c=13; N_t=16)
	Mood Impacts (N_c=6; N_t=10)
	Caregiving Impacts (N_c=7; N_t=9)
Better Understanding of Sleep: Changes to caregivers' understanding of and appreciation for sleep	Learning about Healthy Sleep (N_c=28; N_t=42)
	Insight into Own Sleep (N_c=29; N_t=42)
	Not Alone in Insomnia (N_c=6; N_t=8)
	Prioritizing Sleep and Self-Care (N_c = 13, N_t=19)