

SHUTi-CARE Member Checking – Results Summary & Brief Survey (Qualtrics HSD)

Start of Block: Systematized member checking



Sleep Healthy Using the Internet - Caregiver Acceptability Research

Summary of SHUTi-CARE Open-Ended Responses

Experiences with SHUTi (an Internet insomnia program) as a caregiver

Background

The purpose of the study was to better understand the unique sleep problems that occur when caregiving. We also wanted to understand how well SHUTi treats these sleep problems for caregivers.

We have attempted to summarize what you and other caregivers told us in your open-ended response on your final survey at the end of the SHUTi-CARE study. We have tried to find common ideas that seemed important to study participants. However, we know that we may have missed some of your thoughts.

We are asking for your help by reviewing this summary and then completing a brief (5-minute) survey to make sure we are adequately describing your experiences.

Instructions

Please review the themes that came out of participants' open-ended responses. As you read about these themes, think if these themes reflect YOUR experience with the SHUTi program. After you have read this summary, please complete the short online survey that follows.

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Experiences with SHUTi as a caregiver: Themes from participant responses

(1)

Appropriateness of SHUTi for caregivers: Ways that the SHUTi program information and recommendations fit for caregivers and were relevant to caregivers.

- a. **Interruptions from nighttime caregiving:** Awakenings are not always due to insomnia, but often due to helping a care recipient.
- b. **Sleep environment difficulties:** Unideal sleep conditions due to restless bedpartners or care recipient needs (e.g., keeping some light on).
- c. **Schedule dependent on others:** Some described challenges following program recommendations due to needing to work around someone else's (often the care recipient's) schedule needs.
- d. **Help for sleep interruptions:** Asks for strategies to help dealing with unpredictable sleep disruptions from caregiving.
- e. **Personalization:** When it came to thoughts on refining content to be more specific to caregivers (as a group), there were differing opinions:
 - i. **Yes:** some felt specific content would be helpful and supportive.
 - ii. **No:** others felt current content could be generalized to their specific situation, and content could never fit everyone's exact situation.

(2) **Feasibility of SHUTi for caregivers:** How well participants, as caregivers, were able to complete the SHUTi program and use the recommendations, along with ideas to help improve this for caregivers.

- a. **Delivery format, convenience, and flexibility:** Many liked the variety and organization of information, and appreciated the ease of accessing SHUTi by the Internet and on one's own time. Some suggested options to access the program like podcasts or a mobile application.
- b. **Program manageable:** Many described that the program did not interfere with their responsibilities.
- c. **Easy to use:** Many indicated the program was easy to use, with step-by-step and straightforward information.
- d. **Too busy:** Being too busy described as a barrier to completing daily diaries and the SHUTi program overall.
- e. **Reminders:** Email reminders identified as an essential part of the intervention, and more reminders could help caregivers stay on-track.

(3) **Behavioral components:** What participants liked and did not like about the behavior change recommendations from SHUTi.

- a. **Sleep window:** Setting (and keeping to) bedtimes and waketimes was commonly identified as the most challenging aspect of SHUTi, but also the most helpful aspect when followed (even though it was hard).
 - i. **Need all sleep possible:** Some were unwilling or unable to give up sleep in the short-term for potential long-term benefits.
 - b. **Sleep diary:** While sometimes difficult to regularly enter, many particularly enjoyed keeping track of their sleep with the diaries.
 - c. **Stimulus control:** Although difficult to do, many found the strategy of keeping the bedroom for sleep alone to be very helpful.
 - d. **Sleep routine:** Overall, many liked that SHUTi helped them get into a healthier, more regular sleep routine.
 - e. **Healthy sleep tools:** Many liked that the program gave specific tools, tips, recommendations, strategies, or approaches to help improve sleep.
- (4) **Anxiety, stress, and overload:** Anxiety, stress, and racing thoughts (both general and caregiving-specific) contributed to insomnia and sometimes made it hard to use SHUTi, but also some found SHUTi tips helpful for managing stress.
- (5) **Varied impacts of SHUTi:** The many ways following the SHUTi program influenced participants by altering their sleep.
- a. **Sleep and daytime performance:** While the initial fatigue and how it might impact the day was worrisome, many felt the long-term improved sleep quality helped them do their daily activities better.
 - b. **Sleep and mood:** Similar to daytime performance, initial fatigue sometimes made mood worse, but many noticed improved mood in time.
 - c. **Prioritizing sleep and self-care:** A major motivator to complete the program, some noted the program helped them by giving permission to focus on their own health needs.
 - d. **Impact on caregiving:** Some noted how getting better sleep helped them provide better care by being more alert and patient and having a routine.
 - e. **Program helpful:** Many commented about the program being helpful for them in a broad, general sense.
 - f. **Would recommend:** Several noted that they would – or did – share program tips with family members or other caregivers.
- (6) **Better understanding sleep:** Ways that engaging with the SHUTi program influenced participants' understanding of sleep – both overall, as well as their own sleep.
- a. **Insight into own sleep:** Many noted that they came to better understand their own sleep patterns and what helped their sleep the most.
 - b. **Learning about healthy sleep:** General education about sleep to counter common sleep myths was helpful.

- c. **Not alone in insomnia:** Some appreciated learning that they were not the only ones to struggle with sleep, but that it is a common problem.

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If you are willing, please now complete this brief survey to share your feedback on the SHUTi CARE Results Summary.

Does this summary match your experience?

- ☐ Yes
- ☐ No
-

(Optional) Explain your response about whether this matches your experience.

Page Break

Do you want to change anything in this summary?

☐ Yes

☐ No

(Optional) Explain your response about whether you want to change anything in this summary.

Page Break

Do you want to add any comments or suggestions?

☐ Yes

☐ No

(Optional) Explain your response about whether you want to add any comments or suggestions.

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Would you like someone from our team to follow-up with you (phone call, email, etc.)?

☐ Yes

☐ No

(Optional) Explain your response about whether you would like someone from our team to follow-up with you.

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(Optional) Please let us know if there anything else you would like to share with us.

End of Block: Systematized member checking
