

NIH Public Access

Author Manuscript

Heart Lung. Author manuscript; available in PMC 2014 September 01

Published in final edited form as:

Heart Lung. 2013 ; 42(5): 339-345. doi:10.1016/j.hrtlng.2013.05.003.

"I'd eat a bucket of nails if you told me it would help me sleep:" Perceptions of insomnia and its treatment in patients with stable heart failure

Laura Kierol Andrews, PhD, APRN, ACNP-BC [Assistant Professor],

Yale University School of Nursing, New Haven Connecticut

Jessica Coviello, DNP, APRN, ANP-BC [Associate Professor], Yale University School of Nursing, New Haven Connecticut

Elisabeth Hurley, MSN, APRN, ACNP-BC [Nurse Practitioner], Massachusetts General Hospital

Leonie Rose, MS, RN [Doctoral Student], and Yale University School of Nursing, New Haven Connecticut

Nancy S. Redeker, PhD, RN, FAHA, FAAN [Professor and Associate Dean of Scholarly Affairs]

Yale University School of Nursing, New Haven Connecticut

Abstract

Background—Poor sleep, including insomnia, is common among patients with heart failure (HF). However, little is known about the efficacy of interventions for insomnia in this population. Prior to developing interventions, there is a need for better understanding of patient perceptions about insomnia and its treatment.

Objectives—To evaluate HF patients' perceptions about 1) insomnia and its consequences; 2) predisposing, precipitating, and perpetuating factors for insomnia; 3) self-management strategies and treatments for insomnia; and 4) preferences for insomnia treatment.

Methods—The study, guided by the "3 P" model of insomnia, employed a parallel convergent mixed methods design in which we obtained qualitative data through focus groups and quantitative data through questionnaires (sleep quality, insomnia severity, dysfunctional beliefs and attitudes about sleep; sleep-related daytime symptoms and functional performance). Content analysis was used to evaluate themes arising from the focus group data, and descriptive statistics were used to analyze the quantitative data. The results of both forms of data collection were compared and synthesized.

^{© 2013} Mosby, Inc. All rights reserved.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Results—HF patients perceived insomnia as having a negative impact on daytime function and comorbid health problems, pain, nocturia, and psychological factors as perpetuating factors. They viewed use of hypnotic medications as often necessary but disliked negative daytime side effects. They used a variety of strategies to manage their insomnia, but generally did not mention their sleep concerns to physicians whom they perceived as not interested in sleep.

Conclusions—HF patients believe insomnia is important and multi-factorial. Behavioral treatments, such as Cognitive Behavioral Therapy, for insomnia may be efficacious in modifying perpetuating factors and likely to be acceptable to patients.

Keywords

insomnia; heart failure; sleep; cognitive behavioral therapy for insomnia; hypnotics

Background

More than 70% of patients with heart failure (HF) report poor sleep,^{1–4} and 50% report insomnia symptoms, including difficulty initiating sleep, maintaining sleep, or awakening too early in the morning.⁵ Data from cross-sectional studies suggest that insomnia is associated with daytime symptoms and negative functional and quality of life outcomes among HF patients who suffer disproportionately from these concerns.^{1,4–7} Hypnotic medications and behavioral treatment, such as cognitive behavioral therapy for insomnia (CBT-I), are efficacious in other populations who have insomnia comorbid with medical and psychiatric conditions, and CBT-I may be particularly beneficial to HF patients because of its durable effects and absence of daytime side effects, compared with hypnotic medications.⁸ However, little is known about its efficacy in HF patients, and information is needed about patient perceptions of the importance of insomnia and its treatment prior to developing and testing behavioral insomnia treatment in this population.

Insomnia is a complaint of disturbed sleep "in the presence of adequate opportunity to sleep that consists of one or more of the following: (1) difficulty in initiating sleep; (2) difficulty in maintaining sleep; or (3) waking too early," ^{9, p 5}, accompanied by non-restorative sleep. HF patients report difficulty falling asleep or prolonged sleep latency (23–47%);^{4,10,11} difficulty maintaining sleep (34–43%),^{4,10,11} and about a third reported waking too early in the morning.^{4,10,11} Rates were higher than those reported by healthy adults recruited from the same community.¹¹ Although sleep disordered breathing (SDB) is also prevalent in about 50% of patients with HF and may contribute to poor sleep quality,¹² SDB did not explain perceived sleep quality¹³ or insomnia symptoms among HF patients.^{5,7,14}

Both poor sleep quality and insomnia have negative daytime consequences in patients with HF. For example, sleep quality and insomnia were associated with poor physical function ⁵ and other dimensions of the Medical Outcomes Study SF-36, ^{1,4} as well as six minute walk test (6MWT) distance,¹ but poor sleep¹⁰ was not associated with V0₂ in another study. In one of few studies that controlled for demographic and clinical covariates, including SDB, insomnia was associated with fatigue, depressive symptoms, excessive daytime sleepiness, self-reported physical function, and shorter 6 MWT distance. Participants with insomnia had five times the odds of being depressed (OR = 5.09; 95% CI = 2.41 - 10.75) and walked

almost 100 feet less on the six minute walk test than those without insomnia.⁵ In another study, patients also described the negative impact of sleep on their daytime function, and sleep disturbance (and excessive daytime sleepiness)¹⁵ were associated with poor medication adherence, an important component of self-care.

Spielman's"3 P" Model provides a framework for assessment of factors contributing to insomnia. Spielman posited that predisposing (e.g., biological, psychological, and social); precipitating (e.g., medical, psychiatric conditions, life stress); and perpetuating (perceptions, cognitions and behaviors) factors contribute to chronic insomnia.^{16,17} Cognitive behavioral therapy for insomnia (CBT-I) is a multi-modal treatment is focused on perpetuating factors – the final common pathway to insomnia. Perpetuating factors for insomnia are often not specific to the comorbid disorder (i.e., HF), but usually are similar across people with conditions comorbid with insomnia.

While a number of studies have evaluated demographic and clinical^{5–7,18} factors and symptoms^{7 6 19} associated with sleep disturbance in general and insomnia in particular among patients with HF, there has been little systematic study of insomnia-related behaviors, perceptions, or cognitions that might be amenable to treatment in this population. Evidence for these perpetuating factors emerges from several studies that found that maladaptive sleep-related behaviors and cognitions, including poor sleep hygiene,⁶ prolonged time in bed, napping¹¹ and psychologic distress²⁰ are common among HF patients and related to poor sleep quality. From a more positive perspective, one qualitative study revealed that HF patients used coping, social support, and managing their daily routine to manage their sleep,²⁰ but the sample was a broad group of HF patients who were not screened specifically for insomnia.

The purpose of this mixed methods study, guided by the "3 P" Model of insomnia,^{13,14} was to elicit HF patients' perceptions about insomnia and its treatment in order to determine the need for and potential feasibility of a randomized clinical trial of CBT-I in this population. The specific aims were to evaluate HF patients' perceptions about 1) insomnia, sleep quality, and its consequences (e.g., daytime symptoms, functioning); 2) predisposing, precipitating, and perpetuating factors for insomnia; 3) self-management strategies and treatments for insomnia; and 4) preferences for insomnia treatment.

METHODS

A parallel convergent mixed methods design²¹ was used. The study employed focus groups to obtain narrative data and questionnaires to obtain quantitative data to describe the clinical and demographic characteristics of the sample and to characterize sleep, insomnia symptoms, dysfunctional beliefs and attitudes about sleep, sleep-related daytime symptoms, and self-reported functional performance.

Sample

A purposive sample of patients with stable HF was recruited from an outpatient HF program. Inclusion criteria were New York Heart Association Functional classification (NYHA) II-IV HF; aged 21 years and older; ability to speak and read English, and at least

mild insomnia, as determined by an Insomnia Severity Index of 8 or higher.²² Exclusion criteria were unstable medical or psychiatric disorders; known diagnosis of SDB; and hospitalization for medical or surgical reasons within the previous month. Participants were screened for inclusion and exclusion criteria by an advanced practice registered nurse (APRN).

Variables and Measures

The Pittsburgh Sleep Quality Index (PSQI)²³ was used to evaluate sleep quality. A global score (possible range 0–21) is computed from component scores (sleep quality, sleep latency and duration, habitual sleep efficacy, sleep disturbances, use of sleep medications and daytime dysfunction). Higher scores indicate poorer sleep quality; and a score > 5 indicates poor sleep quality. It is sensitive and specific in differentiating between "good" and "poor" sleepers, valid in comparison with polysomnography,²³ and reliable as a measure of sleep in HF patients.^{1,11}

The Insomnia Severity Scale (ISI),²² was used to measure insomnia. It consists of sevenitems that are scored on a 0–4 scale (total scoring range potential of 0–28). Higher scores indicate a greater severity of insomnia. The ISI is reliable and valid, with acceptable internal consistency^{22,24} and sensitive to change due to insomnia treatment.^{25–27}

Items from the Sleep Heart Health Study Sleep Habits Questionnaire ²⁸ were used to elicit the frequency of insomnia symptoms and factors perceived to influence sleep quality (nocturia, pain, chest pain, shortness of breath, heart burn), as well as noise. Consistent with methods used in the Sleep Heart Health Study²⁸ and a recent study of insomnia in HF⁵ the factors was scored as present if the response was "often" or "almost always" during the past month.

Sleep-related beliefs and attitudes were measured with the modified Dysfunctional Beliefs and Attitudes about Sleep Scale (DBAS).^{29,30} The 16-item DBAS is rated on a 0–10 score (higher score indicated more dysfunctional beliefs), internally consistent (Cronbach's alpha=0.79) and has temporal stability (r = 0.83).²⁹ A score of 3.8 has been shown to distinguish insomnia patients from normal sleepers.³¹

Three sleep-related daytime symptoms (excessive daytime sleepiness, fatigue, depression) and self-reported functional performance were evaluated. The eight-item Epworth Sleepiness Scale (ESS) was used to measure excessive daytime sleepiness. The ESS is scored on a scale of 0–3, with a potential global score of 24. Scores higher than 10 indicate excessive daytime sleepiness.^{32,33} The ESS discriminates between patients with sleep disorders causing sleepiness and those who do not^{32,33} and is reliable and valid in a variety of populations, including people with HF.¹¹ A single item eliciting fatigue severity (0–10 scale) from the Multi-Dimensional Assessment of Fatigue Scale (MAFS)³⁴ was used to evaluate fatigue. Single item measures are reliable and valid measures of symptoms.³⁵ Depressive symptoms were assessed with the Centers for the Epidemiological Studies of Depression Scale (CEDS),^{36,37} a reliable and valid measure of depression, and anxiety was assessed with the Spielberger State-Trait Anxiety Inventory.³⁸

The sub-scale scores of the Medical Outcomes study (MOS) SF 36V2 Health Survey, a well-validated measure, were used to measure function and quality of life.³⁹ This instrument has well-documented reliability and validity in HF and other populations.^{39–42}

PROCEDURE

Institutional review board approval was obtained, and potential participants were contacted by their HF provider to elicit their interest in participating. They were contacted; the study was explained; and all provided written informed consent and completed the study questionnaires prior to the focus groups.

The focus groups were led by an APRN who began the meetings by explaining the purpose of the study and focus group procedures and established ground rules, including the need to allow everyone to speak and the need to assure confidentiality of information discussed. Each session lasted 75–80 minutes and participants were reimbursed \$25 for their time

A semi-structured interview guide, organized according to Spielman's 3P Model of insomnia,^{43,44} was used to elicit participants' perceptions of the importance and consequences of insomnia; predisposing, precipitating, and perpetuating factors; strategies used to manage insomnia and perceptions about treatment (Table 1). Probes and follow-up questions were used, with ample time allowed for discussion and additional comments and clarification.

To ensure the trustworthiness and credibility of the qualitative data, questions were posed so that all participants responded and were able to compare and contrast, or agree or disagree with each other's answers. All meetings were audio-recorded, and the principal investigator (PI) and research assistant (RA) took notes on participant responses, body language, and group process during the meetings. After each session, the PI and RA reviewed the notes and clarified and provided additional notations where needed.

Two focus groups were conducted. Giving the remarkable similarity of the results of both groups, it was evident that saturation was obtained and it was deemed that no additional sessions were needed. Finally, four participants returned for a second focus group to review the findings and verify accuracy.^{45,46}

Data Analysis

The *Statistical Package for the Social Sciences* version 16 (IBM, 2010) was used to compute descriptive statistics, including frequencies, ranges, medians, means, and standard deviations. Medians were used where the data were skewed. The recordings of the focus groups were transcribed by a professional transcriptionist, and the data were imported into the Atlas.ti program (Scientific Software Development, 2009). The PI and a PhD student conducted initial coding to organize the narrative data into mutually exclusive categories and then clustered the resulting codes to identify central themes.⁴⁷ Two additional investigators reviewed the results and confirmed the clustered results. All of the investigators had experience working with HF patients; one had experience in sleep research

and practice. Four participants participated in a follow-up meeting after the focus group session to review the findings. They confirmed the themes and qualitative findings.

RESULTS

The sample consisted of six men and five women who ranged in age from 50–91 years. The majority of participants were white, married or widowed, lived alone and were retired. Participants had New York Heart Association Class II or III HF and had a variety of comorbid conditions (See table 2). Medications are listed in table 3. The most commonly used classes were beta-blockers, aspirin, and statins. Of particular relevance to insomnia, three participants used hypnotic medications, four used anxiolytics, and four took anti-depressants.

Perceptions about sleep/insomnia: "Terrible Sleep"

Participants universally reported poor sleep and insomnia symptoms and described sleep quality as follows: "I've been messed up with sleep for quite a while," "lousy terrible sleeper" and "when I go to bed—a lot of trouble." They described difficulty with falling asleep. For example, comments included the following: "I toss and turn;" "It takes me four or five hours to fall asleep;" "it's just going to bed, trying to sleep at night that's my problem;" and "couldn't fall asleep right away." Waking after sleep onset was also common. One man said "I wake up and can't get back to sleep" and "I went to bed at 12:30, I was up at 1:30, then up again at three am and then four—I say the hell with it and I put the TV on."

Consistent with the focus group results, all participants had scores of 8 or higher on the PSQI, exceeding the cut-off of 5 used to indicate poor sleep quality. (See table 4). Scores on the ISI reflect moderate insomnia. Participants reported difficulty falling sleep (N = 8); awakening after sleep onset (N = 7); waking too early in the morning (N = 4); insufficient sleep (N=5); and feeling unrested (N = 5) often or almost always. On average, participants reporting sleeping for 5.18 ± 0.87 hours per night and seven reported abnormal time to fall asleep (sleep onset latency > 30 minutes)., Nine rated their sleep as "fairly to very bad."

Consequences of poor sleep/insomnia: "Tired of Being Tired"

All of the participants described the negative impact of insomnia on their physical and psychological well-being and quality of life. They attributed daytime tiredness, fatigue, inability to get out of bed in the morning and "accidental" napping to their insomnia symptoms. One stated "I can't function because I'm tired all the time." Another stated he felt "lousy...I would be so tired that I couldn't do much of anything." A woman who was taking care of her ill husband (in addition to managing her own HF) wished she could get "just four straight hours of sleep, then I think I would feel pretty good. Now I have to force myself out of bed." Insomnia often led to inability to do or enjoy previously enjoyable activities, such as concerts, traveling, shopping or visiting with grandchildren.

Most participants were retired or semi-retired and felt they were missing out on what should be the time of life where they are able to take pleasure in having free time. They were plagued with memory problems, stating that their "minds were not what they used to be" and perceived that their memory problems are worse after "a bad night." "I used to have a

perfect memory, now I can't remember my own name." The physical and psychological consequences of insomnia led to isolation and self-pity: "I just feel sorry for myself sometimes. Everyone else can sleep." Others nodded solemnly in affirmation and were then quiet after this statement. It was several moments before anyone would talk again.

Data from the symptom and functional performance questionnaires (table 4) revealed that six participants were depressed (CESD 16). However, scores on trait and state anxiety were comparable to the 50th to 75th percentile (low) for older adults.^{48,49} With the exception of the bodily pain subscale of the MOS SF-36, the other sub-scale scores were comparable to those previously reported on patients with New York Heart Class II-III HF.⁵⁰ The bodily pain score was considerably lower (worse) than the scores for HF patients in other studies who did not have insomnia.⁵⁰ Two participants were excessively sleepy (ESS > 10) and overall levels of fatigue were high, as indicated by a median score of 7 on a 0–10 scale on the Global Fatigue Scale.

Factors associated with Insomnia

Participants were not able to describe predisposing factors for insomnia. However, all but three participants, identified HF as the primary initiating (precipitating) factor and agreed that they were always "good at sleeping" prior to the onset of HF. One woman noted that she suffered childhood abuse. Her father was "a drunken alcoholic and we never slept when we were children, so why sleep now?" and stated that she has had bouts of depression since childhood that have a negative impact on her sleep. One man who was a retired police officer believed his insomnia was initially caused by working rotating shifts, "screwy shifts, especially midnights." He indicated that hyper-vigilance necessary on the night shift led to his insomnia. The third participant, a military veteran, suffered from Post-Traumatic Stress Disorder (PTSD) "panic attacks," which he identified as the predisposing cause of his insomnia.

Perpetuating factors identified included ongoing comorbid and psychological conditions. Comorbid contributors included dysrhythmias, discomfort from pacemakers or internal cardiac defibrillators (ICD), diabetes, strokes, adverse reactions to cardiac medications (e.g., diuretics and amiodarone) and obesity. Two men who had pacemaker/ICDs described difficulty sleeping on their left sides due to the position of the device. All of the participants suffered from pain syndromes such as neuropathy, chronic back pain, arthritis, post-herpetic neuralgia and carpal tunnel syndrome that made it difficult to fall and stay asleep.

No one attributed insomnia to HF symptoms such as orthopnea or paroxysmal nocturnal dyspnea, but nocturia, a symptom that is also common in the general population (especially older adults),⁵¹ was prevalent. Several participants, especially men, attributed waking after sleep onset to nocturia, but they could not decide if they awakened due to having to urinate or if they noticed the need to urinate after awakening. Responses to the Sleep Habits Questionnaire were consistent with the qualitative findings. Participant perceived that nocturia (N = 9) and pain (N = 9) often or almost always contributed to insomnia. Fewer participants perceived other contributors [night sweats (N=3), shortness of breath (N =2), heart burn (N = 2), and chest pain (N =2)] awoke them often or almost always. Six participants reported that noise contributed to poor sleep (N =6).

Participants also identified psychological conditions including depression, anxiety, fear, panic attacks and post-traumatic stress disorder that contributed to their insomnia. They worried about their families, friends, and finances and about not being able to fall asleep and wished they could stop the thoughts and led to the self-fulfilling prophecy of insomnia. "I go to bed knowing that I'm not going to sleep and it bothers me…Oh dear God, please let me sleep tonight." This statement was met with confirmation by subjects who nodded yes and stating "me too." Fear of being alone, having trouble breathing, dying and "the long night ahead" were distressing for most of the women. One stated "I have that terrible feeling" at night. A man who suffered from undiagnosed PTSD due to his wartime experience, described having "to go room to room, then out on the front steps to catch my breath" when he has a panic attack.

The mean and median scores on the dysfunctional beliefs and attitudes about sleep scale (DBAS) were higher than the published cut-off of 3.8 that distinguishes insomnia patients.³¹ The highest rated beliefs and attitudes about sleep (0–10 scale) were indicators of the perceived negative consequences of sleep on health (median = 9) and attributions of poor psychological functioning (median = 8) and feeling tired (median = 7) to poor sleep. Perceived lack of control over sleep was high (median = 7), and participants often endorsed the ideas that they needed 8 or more hours of sleep to function (median = 6) and that medications were the only solution (median = 5). However, the perception that a single night of poor sleep was likely to have a major negative impact on their daytime function was low (medians ranged 2–3).

Insomnia management strategies

Four themes emerged related to insomnia management: "mind games," "managing daily activity," "Sleep medications: can't live with them, can't live without them;" and "Docs Don't Ask, We Don't Tell." (Table 5)

"Mind games." Nighttime routines included playing "mind-games" to distract themselves from insomnia, worries and fears. The most common was going to bed late and watching television until falling asleep. One participant would set the television timer and try to beat the "TV to sleep." Others used distraction through music, reading or driving in the car. Participants reported that they "fooled" their minds into going to sleep.

"Managing daily activities" included staying active, having an enjoyable activity to look forward to each day and "getting something done" daily to manage their insomnia. They felt that being active "even if it's just washing the car" was a way to keep a positive attitude, and helped them sleep better at night. Although eight patients reported napping once or more during the day, participants did not view napping as helpful in relieving fatigue resulting from poor sleep.

"Sleep medications: can't live with them, can't live without them." Seven participants reported using anxiolytic or hypnotic medications to help them sleep at least once a week, but most used them "only if absolutely necessary." They decided on a nightly basis whether to take the pills and questioned their need for them, especially if they needed to be able to function fully the next day. All feared the need to "have to" take sleeping medication

because they reported feeling "hung-over," "groggy, "like a zombie" and hallucinating, as well as potential dependency and addiction. One participant reported that she would "just nibble a little bit off" her pill at night and rationalized, "it was not like taking the whole dose." Another participant took a family member's 3-mg eszopiclone, rather than her own prescribed 10-mg zolpidem, because the former "isn't as strong, so it's not as bad." Responses to the sleep medication item on the PSQI revealed that seven participants took prescribed or over-the-counter medications at least once per week during the past month.

"Docs Don't Ask, We Don't Tell." Although participants wanted relief from insomnia, they rarely if ever mentioned this concern to physicians whom they perceived as "just taking your blood and giving you another pill." "They don't pay personal attention and I don't want another pill." They wanted their physicians to ask "how they are sleeping, "and mentioned that only the nurse practitioner (who was an investigator on the study) asks about their sleep. They were interested in educational and behavioral strategies to help them sleep and would be willing to take "try anything", especially if it decreased their dependence on sleep medications. When asked about their potential interest in behavioral sleep treatment, one participant stated: "I'd eat a bucket of nails if it you told me it would help me sleep." This was greeted with a resounding chorus of "me too." The majority of the group agreed that they would like to learn more about sleep and insomnia and behavioral strategies to address it. When presented with the option of group or individual treatment, they viewed both as acceptable.

Discussion

The findings of this multi-method study indicate that HF patients had poor sleep quality and high levels of concern about insomnia and its impact on health and daily function. For the most part, the data from the qualitative and quantitative assessments were consistent. Similar to the results of an earlier phenomenological study²⁰ and associations found in more recent observational studies,^{1,4,5,7,15,18} participants consistently attributed poor daytime physical, psychological and social function to insomnia. Unlike past studies, the sample consisted entirely of patients with insomnia symptoms, and our study was guided by the "3-P" Model of insomnia.

Although most participants described HF as the primary precipitating factor for insomnia, they perceived that the influences on sleep/insomnia were multifactorial and included the effects of HF-related treatment (e.g., medications and devices), as well as other comorbid conditions, such as diabetes. Psychological concerns and noise were also important considerations.

The finding that nocturia and pain, but not shortness of breath, were frequently reported perpetuating factors is notable, as both Riegel and colleagues⁶ and Redeker and colleagues¹⁹ found that nocturia was common and associated with poor sleep among HF patients. Redeker and colleagues found that nocturia was the most common of nocturnal symptoms to influence sleep (unpublished data). Although nocturia is often considered to be a HF-specific symptom, it is also prevalent in the general population.⁵¹ Pain was also common

and levels were very high in comparison to previously reported scores for patients with $\mathrm{HF}.^{50}$

Similar to the broader population of patients with chronic insomnia, worries and fears were commonly identified psychological perpetuating factors for insomnia. Some but not all, of these worries pertained to the diagnosis of HF. These reports were consistent with evidence that the majority of participants were depressed and four used anti-depressants. Although state and trait anxiety levels were in the mid-low ranges as compared to normative data on older adults,^{48,49} four patients were on prescribed anxiolytics that may have influenced these results.

Although patients and clinicians often presume that symptoms, such as nocturia and pain, as well as psychological symptoms, such as worries, fears, and mood disorders, contribute to insomnia, the converse may also be true: Both nocturia⁵¹ and pain,⁵² as well as psychological distress may be consequences, as well as causes of poor sleep or insomnia. There is a pressing need for studies of the causal relationships among these phenomena. Likewise, behavioral insomnia treatment may improve depression,⁵³ as well as pain,⁵⁴ but the extent to which insomnia treatment improves nocturia is not known.¹⁹

Dysfunctional beliefs and attitudes about sleep are important in the perpetuation of insomnia. Examples include catastrophic thinking about the impact of poor sleep, inaccurate perceptions regarding controllability, or the belief that sleeping less than eight hours will result in negative outcomes. These beliefs may lead to elevated levels of anxiety about sleep³¹ and thus, lead to a vicious cycle that perpetuates poor sleep. High scores on the DBAS scale, as well as many comments obtained in the focus groups, indicate the presence of such beliefs in this group of HF patients.

Participants used a variety of cognitive, behavioral, and pharmacological strategies to manage their insomnia. Some (e.g., getting exercise and developing patterns of activity during the day) were reported in a previous qualitative study of HF patients²⁰ and are often included in sleep hygiene and stimulus control instruction, components of CBT-I. On the other hand, a number of behaviors that participants described, such as keeping the television on until falling asleep or tossing and turning at night without getting out of bed, are practices that are likely to have a negative impact on sleep and should be the focus of intervention.

Our findings regarding the perpetuating factors for insomnia and participants' perspectives regarding treatment strategies provide important information in support of the development of behavioral treatment for insomnia among HF patients. Notably, many of the factors associated with insomnia (e.g., precipitating factors, pain, worries) are not specific to the diagnosis of HF itself, but the effects of these conditions and insomnia may worsen daytime function in these vulnerable patients. Although evidence-based management of HF may contribute to improvements in sleep, it doesn't focus on factors that are not specific to HF, including perceptions and behaviors. Cognitive behavioral therapy (CBT-I), a treatment that focuses on addressing cognitive, perceptual, and behavioral perpetuating factors – many of which were identified in this study – holds promise as an efficacious treatment in this population. HF patients' dissatisfaction with hypnotic treatment and strong motivation to

address insomnia suggest the potential for high levels of acceptability of behavioral treatment.

Our findings underscore the critical importance of evaluating sleep, including insomnia. When hypnotics are prescribed, it is important to address the potential for daytime dysfunction, as well as the potential negative effects of hypnotics on respiratory function in patients with comorbid sleep disordered breathing. Over-the-counter medications and herbal preparations have little documented efficacy and may have negative interactions with prescribed medications. Many over-the-counter medications include diphenhydramine that often results in daytime drowsiness, especially in older adults. Although further studies of the efficacy of CBT-I for insomnia are needed to evaluate its efficacy in HF patients, CBT-I is already available in many sleep disorders centers and may afford relief for HF patients.

Limitations

A limitation of this study was recruitment of participants from a single practice in one geographical location. Because we relied on self-report regarding history of primary sleep disorders, it is possible that participants had sleep disorders, such as sleep disordered breathing, that were undetected and contributed to insomnia symptoms. However, SDB and insomnia are often comorbid^{5,12} and in our previous study, we found that these conditions were not associated with one another in HF patients.^{5,13} Additionally, we reached saturation in the qualitative data with a small sample size; it is a limitation in relations to the quantitative data.

Conclusions

Insomnia is common among patients with HF who express concerns about its impact on their health and function; the lack of attention to this problem by health care providers; and dissatisfaction with use of pharmacological treatment, as well as the multi-dimensional cognitive and behavioral contributing factors, suggest the potential acceptability and usefulness of behavioral treatment for insomnia in this vulnerable population.

Acknowledgments

Funding: This study was funded by the Yale School of Nursing Center for Self and Family Management in Vulnerable Populations (grant #: P30NR08999)

References

- Redeker NS, Hilkert R. Sleep and quality of life in stable heart failure. J Card Fail. 2005; 11(9):700– 704. [PubMed: 16360966]
- 2. Redeker NS. Sleep disturbance in people with heart failure: implications for self-care. J Card Nurs. 2008; 23(3):231–238.
- Johansson P, Arestedt K, Alehagen U, Svanborg E, Dahlstrom U, Brostrom A. Sleep disordered breathing, insomnia, and health related quality of life -- a comparison between age and gender matched elderly with heart failure or without cardiovascular disease. Eur J Cardiovasc Nurs. 2010; 9(2):108–117. [PubMed: 20056491]
- 4. Brostrom A, Stromberg A, Dalstrom U, Fridlund B. Sleep difficulties, daytime sleepiness, and health-related quality of life in patients with chronic heart failure. J Card Nurs. 2004; 19(4):234–242.

- Redeker NS, Jeon S, Muench U, Campbell D, Walsleben J, Rapoport DM. Insomnia symptoms and daytime function in stable heart failure. Sleep. 2010; 33(9):1210–1216. [PubMed: 20857868]
- 6. Riegel B, Glaser D, Richards K, et al. Modifiable factors associated with sleep dysfunction in adults with heart failure. Eur J Cardiovasc Nurs. 2011; 23:23.
- 7. Principe-Rodriguez K, Strohl KP, Hadziefendic S, Pina IL. Sleep symptoms and clinical markers of illness in patients with heart failure. Sleep Breath. 2005; 9(3):127–133. [PubMed: 16086163]
- Morin CM. Cognitive-behavioral approaches to the treatment of insomnia. J Clin Psychiatry. 2004; 65(Suppl 16):33–40. 2004. [PubMed: 15575803]
- 9. National Institutes of Health State of the Science Conference Statement. Manifestations and management of chronic insomnia in adults. Sleep. 2005; 28:1049–1057. [PubMed: 16268373]
- Erickson VS, Westlake CA, Dracup KA, Woo M, Hage A. Sleep disturbance symptoms in patients with heart failure. AACN Clinical Issues. 2003; 14(4):477–487. [PubMed: 14595207]
- 11. Redeker NS, Stein S. Characteristics of sleep in patients with stable heart failure versus a comparison group. Heart Lung. 2006; 35(4):252–261. [PubMed: 16863897]
- Lavie P. Insomnia and sleep-disordered breathing. Sleep Med. 2007; 8(Suppl 4):S21–S25. [PubMed: 18346673]
- Redeker NS, Muench U, Zucker MJ, et al. Sleep disordered breathing, daytime symptoms, and functional performance in stable heart failure. Sleep. 2010; 33(4):551–560. [PubMed: 20394325]
- Johansson P, Alehagen U, Svanborg E, Dahlstrom U, Brostrom A. Sleep disordered breathing in an elderly community-living population: Relationship to cardiac function, insomnia symptoms and daytime sleepiness. Sleep Med. 2009; 10(9):1005–1011. [PubMed: 19464948]
- Riegel B, Moelter ST, Ratcliffe SJ, et al. Excessive Daytime Sleepiness is Associated With Poor Medication Adherence in Adults With Heart Failure. J Card Fail. 2011; 17(4):340–348. [PubMed: 21440873]
- Spielman AJ, Caruso LS, Glovinsky PB. A behavioral perspective on insomnia treatment. Psych Clin North Am. 1987; 10(4):541–553.
- Perlis, ML.; Smith, MT.; Pigeon, WR. Etiology and pathophysiology of insomnia. In: Kryger, MH.; Roth, TH.; Dement, WC., editors. Principles and Practice of Sleep Medicine. 4th ed. Philadelphia: Elsevier Saunders; 2005. p. 714-725.
- 18. Johansson P, Arestedt K, Alehagen U, Svanborg E, Dahlstrom U, Brostrom A. Sleep disordered breathing, insomnia, and health related quality of life -- a comparison between age and gender matched elderly with heart failure or without cardiovascular disease. Eur J Card Nurs. 2010; 9(2): 108–117.
- Redeker NS, Adams L, Berkowitz R, et al. Nocturia, sleep and daytime function in stable heart failure. J Card Fail. 2012; 18(7):569–575. [PubMed: 22748491]
- 20. Brostrom A, Stromberg A, Dahlstrom U, Fridlund B. Patients with congestive heart failure and their conceptions of their sleep situation. J Adv Nurs. 2001; 34(4):520–529. [PubMed: 11380719]
- 21. Creswell, JW.; Plano Clark, VL. Designing and Conducting Mixed Methods Research. 2d ed. Thousand Oaks, CA: Sage; 2011.
- 22. Bastien CH, Vallieres A, Morin CM. Validation of the Insomnia Severity Index as an outcome measure for insomnia research. Sleep Med. 2001; 2(4):297–307. [PubMed: 11438246]
- Buysse DJ, Reynolds CF, Monk TH, Berman SR, Kupfer DJ. The Pittsburgh Sleep Quality Index: a new instrument for psychiatric practice and research. Psychiatry Res. 1989; 28(2):193–213. [PubMed: 2748771]
- Blais FC, Gendron L, Mimeault V, Morin CM. [Evaluation of insomnia: validity of 3 questionnaires]. Encephale. 1997; 23(6):447–453. [PubMed: 9488928]
- Bastien CH, Morin CM, Ouellet MC, Blais FC, Bouchard S. Cognitive-behavioral therapy for insomnia: comparison of individual therapy, group therapy, and telephone consultations. J Cons Clin Psychol. 2004 Aug; 72(4):653–659.
- Smith S, Trinder J. Detecting insomnia: comparison of four self-report measures of sleep in a young adult population. J Sleep Res. 2001; 10(3):229–235. [PubMed: 11696076]

- Yang M, Morin CM, Schaefer K, Wallenstein GV. Interpreting score differences in the Insomnia Severity Index: using health-related outcomes to define the minimally important difference. Curr Med Res Opin. 2009; 25(10):2487–2494. [PubMed: 19689221]
- Baldwin CM, Griffith KA, Nieto FJ, O'Connor GT, Walsleben JA, Redline S. The association of sleep-disordered breathing and sleep symptoms with quality of life in the Sleep Heart Health Study. Sleep. 2001; 24(1):96–105. [PubMed: 11204058]
- 29. Morin CM, Vallieres A, Ivers H. Dysfunctional beliefs and attitudes about sleep (DBAS): validation of a brief version (DBAS-16). Sleep. 2007; 30(11):1547–1554. [PubMed: 18041487]
- Buysse DJ, Ancoli-Israel S, Edinger JD, Lichstein KL, Morin CM. Recommendations for a standard research assessment of insomnia. Sleep. 2006; 29(9):1155–1173. [PubMed: 17040003]
- Carney CE, Edinger JD, Morin CM, et al. Examining maladaptive beliefs about sleep across insomnia patient groups. Journal of psychosomatic research. 2010; 68(1):57–65. [PubMed: 20004301]
- Johns MW. Reliability and factor analysis of the Epworth Sleepiness Scale. Sleep. 1992; 15(4): 376–381. [PubMed: 1519015]
- Johns MW. A new method for measuring daytime sleepiness: The Epworth Sleepiness Scale. Sleep. 1991; 14(6):540–545. [PubMed: 1798888]
- 34. Piper, B.; Lindsey, A.; Dodd, M.; Ferketich, S.; Paul, S.; Wellver, S. The development of an instrument to measure the subjective dimensions of fatigue. In: Funk, S.; Tornquist, E.; Champagne, M.; Wiese, R., editors. Key aspects of comfort: Management of pain, fatigue, and nausea. New York: Springer; 1989.
- Youngblut JM, Casper GR. Single-item Indicators in Nursing Research. Res Nurs Health. 1993; 16:459–465. [PubMed: 8248573]
- 36. Radloff LS. The CES-D Scale: A self report depression scale for research in the general pupulation. Appl Psychol Meas. 1977; 1:385–401.
- Radloff LS, Teri L. Use of the Center for Epidemiological Studies-Depression Scale with older adults. Clin Gerontol. 1986; 5(1/2):119–136.
- Spielberger, CD. Manual for the State-Trait Anxiety Inventory STAI-Form Y. Palo Alto, CA: Consulting Psychologists Press; 1983.
- 39. Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I.Conceptual framework and item selection. Med Care. 1992; 30(6):473–483. [PubMed: 1593914]
- 40. Ware, JE, Jr. [Accessed February 8, 2006] SF-36® Health Survey Update. 2002. http:// www.sf-36.org/tools/SF36.shtml
- 41. Ware, JE. SF-36 Physical and Mental Health Summary Scales: A User's Manual. Boston: The Health Institute, New England Medical Center; 1994.
- 42. Ware, JE. Health Survey Manual and Interpretation Guide. Boston: Health Institute, New England Medical Center; 1993.
- Spielman, A.; Glowinsky, P. The natural history of insomnia. In: Hauri, P., editor. Case studies in insomnia. New York: Plenum Press; 1991. p. 1-15.
- 44. Spielman AJ, Nunes J, Glovinsky PB, Yang CM, Glovinsky P. Nonpharmacologic strategies in the management of insomnia. Neurol Clin. 1996; 14(3):513–543. [PubMed: 8871975]
- 45. Beck CT. Critiquing qualitative research. AORN J. 2009; 90(4):543-554. [PubMed: 19801006]
- 46. Streubert, HJ.; Carpenter, DR. Qualitative Research in Nursing: Advancing the Humanistic Imperative. 2 ed. Philadelphia: Lippincott; 1999.
- 47. Krippendorff, KH. Content Analysis: An Introduction to Its Methodology. 2 ed. Thousand Oaks, CA: Sage; 2004.
- Bergua V, Meillon C, Potvin O, et al. The STAI-Y trait scale: psychometric properties and normative data from a large population-based study of elderly people. Int Psychogeriatr. 2012; 24(7):1163–1171. [PubMed: 22436140]
- 49. Potvin O, Bergua V, Meillon C, et al. Norms and associated factors of the STAI-Y State anxiety inventory in older adults: results from the PAQUID study. Int Psychogeriatr. 2011; 21:1–11.

- 50. Juenger J, Schellberg D, Kraemer S, et al. Health related quality of life in patients with congestive heart failure: comparison with other chronic diseases and relation to functional variables. Heart. 2002; 87(3):235–241. [PubMed: 11847161]
- Bliwise DL, Foley DJ, Vitiello MV, Ansari FP, Ancoli-Israel S, Walsh JK. Nocturia and disturbed sleep in the elderly. Sleep Med. 2009; 10(5):540–548. [PubMed: 18703381]
- 52. Dzierzewski JM, Williams JM, Roditi D, et al. Daily variations in objective nighttime sleep and subjective morning pain in older adults with insomnia: evidence of covariation over time. J Am Geriatrics Soc. 2010 May; 58(5):925–930.
- Manber R, Edinger JD, Gress JL, San Pedro-Salcedo MG, Kuo TF, Kalista T. Cognitive behavioral therapy for insomnia enhances depression outcome in patients with comorbid major depressive disorder and insomnia. Sleep. 2008; 31(4):489–495. [PubMed: 18457236]
- Jungquist CR, O'Brien C, Matteson-Rusby S, et al. The efficacy of cognitive-behavioral therapy for insomnia in patients with chronic pain. Sleep Medicine. 2010; 11(3):302–309. [PubMed: 20133188]

Focus Group Guide

Introduction

- Welcome by the Principal Investigator
- Introduction of the Research Assistant
- Name tags for each participant
- Review the purpose of the study
- Review the use of tape-recorder and rationale for note taking

Ground Rules

- Confidentiality of information by research team and each participant
- Respect for each other's person, comments, and feelings
- One person speaking at a time

Questions

- 1 How is your sleep?
- 2 When did you first realize that you had problems with your sleep?
- 3 How was your sleep prior to developing heart failure?
- 4 How was your sleep after developing heart failure?
- 5 Do you think your heart failure worsened your sleep?
- 6 What do you think caused your insomnia?
- 7 What are your symptoms of insomnia?
- 8 What is it that you do to manage or treat your insomnia?
- 9 Do you take any prescription or over the counter drugs or suppliments to help you sleep better? What are they?
- 10 How does your insomnia affect you? Your day to day activities?
- 11 Do your health care providers ask you about sleep? (if not—Have you told them you have problems with sleeping?
- 12 How would you like your health care providers to help you with your sleep?
- 13 Do you think that you would participate in an insomnia program that uses non-medication therapy to help you manage your insomnia?

Demographic and clinical characteristics of Participants (N=11)

Demographic Characteristics	N/M (SD)
Male	6 (54.6)
Female	5 (45.6)
Age (yrs)	71.6 (12.1)
Range	50–91
Race	
White	10
Black	1
Marital Status	
Single	2
Married	4
Divorced	1
Widowed	4
Resides	
Alone	7
With spouse	4
Employment	
Retired	8
Disabled	2
Part-time	1
Clinical Characteristics/Health History	
Cardiovascular	
NYHA Functional Classification	
П	2
III	9
Pacemaker/ICD	2
Angioplasty	5
Coronary Artery Bypass Graft	3
Angina	3
Myocardial Infarction	4
Hypertension	5
Atrial Fibrillation	1
Ventricular Fibrillation/Tachycardia	2
Neurological	
CVA	1
Peripheral Neuropathy	2
Musculoskeletal	
Osteoarthritis	2
Chronic Back Pain	2
Gout	2

Page 1	17
--------	----

Demographic Characteristics	N/M (SD)
Endocrine	
Diabetes	4
Hypothyroidism	2
Respiratory	
Asthma	1
Urinary	
Benign Prostatic Hypertrophy	2
Renal Failure	0

Prescribed Medications (N = 11)

Medication Classification	N
Beta-Blockers	7
ACE-Inhibitors	3
ARBs	4
ASA	5
Dyslipidemics	
Statins	7
Fibrinates	1
Omega-3	2
Other	2
Nitrates	1
Calcium Channel Blockers	2
Digoxin	2
Warfarin	2
Diuretics	
Loop	7
K-Sparing	2
Diabetes	
Insulin	3
Oral	1
Antidepressants	
SSRI	1
SNRI	1
St. John's Wort	1
Other	1
Pain-relievers	
Opiates	3
Anti-Neuroleptics	4
Topical	1
OTC	11
Anxiolytics	4
Hypnotics	3
Vitamin/Mineral Supplements	8

OTC: over the counter

Descriptive Statistics: Sleep Quality, Insomnia, Daytime Symptoms, and Functional Performance

Variables/Measures	Range	Median	Mean(S D)
Sleep Quality (Pittsburgh Sleep Quality Index)	8-18	13	13.64(2.91)
Insomnia Severity (Insomnia Severity Index)	11-24	17	16.55 (4)
Dysfunctional Beliefs & Attitudes about Sleep Scale	2.13-8.06	4.25	5 (1.86)
Depressive Symptoms (CESD)	7–43	20	19.55 (10.78)
State-Anxiety (STAI-Y)	22-62	41	40.36 (10.26)
Trait-Anxiety (STAI-Y)	28-66	47	42.86 (11.17)
Fatigue (Global Fatigue Scale)	3-10	7	7.09 (2.51)
Daytime Sleepiness (Epworth Scale)	4-8	9	8.82 (4.05)
Physical Function (SF36v2)	9–95	40	38.18 (23.8)
Role Physical (SF36v2)	25-100	37.5	44.32 (23.29)
Bodily Pain (SF36v2)	22-61	31	34.27 (13.22)
General Health (SF36v2)	10-82	45	48 (19.27)
Vitality (SF36v2)	0-81	43.75	43.75 (23.88)
Social Function (SF36v2)	38-100	75	69.32 (20.44)
Role Emotional (SF36v2)	8-100	58.33	58.33 (27.64)
Mental Health (SF36v2)	10-90	70	62.27 (28.49)

Content Analysis Themes

- Tired of Being Tired
- Terrible Sleep
- Co-Morbid Contributors
- Psychological Perpetuators
- Mind Games
- Managing Daily Activities
- Sleep Meds: Can't Live With Them, Can't Live without Them
- Docs Don't Ask & We Don't Tell