Published in final edited form as:
Psychooncology. 2010 October ; 19(10): 1086–1093. doi:10.1002/pon.1664.

Sleep-Wake Functioning Along the Cancer Continuum: Focus Group Results From the Patient-Reported Outcomes Measurement Information System (PROMIS™)

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Abstract

Objective—Cancer and its treatments disturb sleep-wake functioning; however, there is little information available on the characteristics and consequences of sleep problems associated with cancer. As part of an effort to improve measurement of sleep-wake functioning, we explored the scope of difficulties with sleep in a diverse group of patients diagnosed with cancer.

Methods—We conducted 10 focus groups with patients recruited from the Duke University tumor registry and oncology/hematology clinics. Separate groups were held with patients scheduled to begin or currently undergoing treatment for breast, prostate, lung, colorectal, hematological, and other cancer types and with patients who were in posttreatment follow-up. The content of the focus group discussions was transcribed and analyzed for major themes by independent coders.

Results—Participants reported causes of sleep disturbance common in other populations, such as pain and restless legs, but they also reported causes that may be unique to cancer populations, including abnormal dreams, anxiety about cancer diagnosis and recurrence, night sweats, and problems with sleep positioning. Many participants felt that sleep problems reduced their productivity, concentration, social interactions, and overall quality of life. Many also shared beliefs about the increased importance of sleep when fighting cancer.

Conclusions—The findings underscore the need for interventions that minimize the negative impact of cancer and its treatments on sleep. This study will inform efforts now underway to develop a patient-reported measure of sleep-wake functioning that reflects the breadth of concepts considered important by patients with cancer.

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Financial Disclosures: None reported.

Keywords

Cancer; Focus Groups; Oncology; Qualitative Research; Quality of Life; Sleep

Introduction

As many as half of people diagnosed with cancer report disturbed sleep [1], and the problems can persist long after treatment has ended [2,3]. Cancer and its treatments disturb multiple aspects of sleep, including difficulty falling asleep, difficulty staying asleep, early awakening, and excessive daytime sleepiness [4]. Although sleep disturbance is distinct from fatigue [5], several studies have found that insomnia, cancer-related fatigue, and other symptoms such as pain and night sweats are highly prevalent, and there are complex patterns of covariation among these symptoms [6–8]. Sleep disturbance in people with cancer is associated with psychological distress [9] and impairments in health-related quality of life [10] and may contribute to hyperalgesia [11].

Emerging research is beginning to identify mechanisms of sleep disturbance in patients with cancer [12]. For example, sleep disturbances, fatigue, and asthenia have been linked to hypothalamic-pituitary-adrenal axis overactivity [13–18], and there is growing evidence that proinflammatory cytokines may play a role in the etiology of several chemotherapy-related symptoms, including sleep-wake disturbances [19].

Although sleep problems are common, only one study has examined the characteristics or consequences of sleep difficulties in patients diagnosed with cancer using qualitative methods [20]. In their mixed-methods study, Engstrom and colleagues found that 45% of patients with breast or lung cancer had experienced sleep disturbances in the past month, and qualitative inquiry indicated that sleep problems were related to the symptom experience and to distressing perceptions of cancer and its treatment. Additional qualitative studies in this heterogeneous patient population are important because the nature of sleep problems can vary by cancer site, treatment type, the patient's position in the continuum of care (from diagnosis to treatment to survivorship and end of life), and comorbid conditions.

Evidence suggests that cancer patients and clinicians do not routinely discuss sleep problems and that a limited range of strategies to manage sleep difficulties are employed [20], despite the availability of effective pharmacological and behavioral treatments [21–23]. Moreover, there is no widely accepted measure of patient-reported sleep-wake disturbance for use in cancer populations. In a review of 15 articles on the prevalence of insomnia in cancer patients, no single measure dominated [24]. About half of the questionnaires used some version of a single question. This approach is problematic; at least one effort to create a single-item screening measure for insomnia in cancer patients was unsuccessful because of poor sensitivity and specificity [25].

Development of a self-reported measure of sleep problems for use in cancer populations is important for several reasons. Polysomnography and actigraphy are costly and not feasible for routine use in oncology, so there is a need for a systematic, sensitive, unified, and nuanced approach to patient-reported measurement of sleep problems. Available measures have undergone limited psychometric evaluation in cancer populations [26], and the relevance of the content domains to the sleep impairments experienced by patients with cancer is unknown. As a result, there is a need to better characterize the nature of sleep-wake difficulties in patients with cancer and to develop validated patient-reported outcome measures. Furthermore, standardizing the assessment of sleep difficulties by self-report would allow for comparisons of conditions across studies or in meta-analyses [27].

The Patient-Reported Outcomes Measurement Information System (PROMIS™) Network (http://www.nihpromis.org/) is a collaborative effort of 7 research universities and the National Institutes of Health to advance the measurement of patient-reported outcomes using state-of-the-art psychometric and computer-adaptive techniques. To enhance the relevance of the PROMIS measures for patients with cancer and support the development of a measure of sleep-wake functioning, we conducted focus groups with individuals with cancer to characterize the nature, scope, and importance of sleep difficulties. The goal of the focus groups was to develop a qualitative summary of the unique and broad spectrum of effects that cancer and cancer treatments can have on patients' sleep-wake functioning.

Methods

Study Design

We recruited focus group participants via mailed invitations to patients in the Duke University tumor registry and in person at the Duke Comprehensive Cancer Center. Eligible participants were aged 18 years or older, had been diagnosed with cancer, and were able to speak English. The purposive sampling strategy aimed for representation with regard to tumor site, phase of treatment (ie, undergoing treatment or in posttreatment follow-up), sex, race, and education level.

We organized a total of 10 focus groups; each group had 6 to 12 scheduled participants. Seven focus groups included participants who were newly diagnosed or currently undergoing treatment for breast, prostate, lung, colorectal, hematological, or other cancer types, and 3 focus groups included participants who were in posttreatment follow-up for any cancer type. Participants had undergone a wide variety of treatments, including surgery, chemotherapy, radiation therapy, hormonal therapy, molecularly targeted therapy, and multimodal treatments. Participants received $75 in compensation and were offered a light dinner. The institutional review board of the Duke University Health System approved the study.

Table 1 shows the demographic and disease characteristics of the participants. Focus group sessions typically lasted 70 to 90 minutes. The prostate cancer groups were led by a male moderator; all other groups were led by a female moderator. The moderators led discussions following a semistructured interview guide developed by the domain committee based on a literature review and clinical experience. The initial guide aimed to gain understanding of the scope and importance of sleep issues for patients with cancer and the physical, mental, and social impacts of cancer on sleep. After analyzing the discussions from the first focus group, we were able to clarify our developing ideas about patients' experiences and concerns. Therefore, we revised the discussion guide to allow for broader conversations about sleep difficulties that may not be attributable directly to cancer or its treatments but are exacerbated by cancer. The revised guide addressed (1) the scope and importance of sleep issues for patients with cancer, (2) the impact of cancer on sleep, (3) the consequences of sleep difficulties for daytime functioning and quality of life, and (4) management of sleep difficulties. Table 2 shows sample questions from the discussion guide.

All focus group sessions were audio-recorded and transcribed. A trained notetaker observed the groups to capture important elements of the interactions. An independent auditor verified a 50% sample of the summaries against the transcripts. The domain committee reviewed these summaries to determine whether any focus group should be repeated to achieve data saturation.

Analysis

The goal of the focus groups was to qualitatively characterize sleep-wake functioning during and after the diagnosis and treatment of cancer; including aspects of the cancer experience that may predispose, precipitate, or perpetuate sleep-wake disturbances. We began with a structured coding scheme based on literature review. Two trained research assistants independently coded all transcripts, meeting regularly with another member of the study team to resolve disagreements in coding and to inductively categorize themes that did not fit the preliminary coding structure. Thus, the preliminary coding scheme was iteratively revised based on participant contributions. We found no new themes after 7 focus groups with patients in active treatment and 3 focus groups with patients in post-treatment follow-up, suggesting that we had achieved data saturation. We used N6 qualitative analysis software (QSR International, Melbourne, Australia) to manage the written transcripts. In addition to describing the different themes, we report the occurrence of each theme at the group level. Quotations offered by participants are provided to illustrate the themes that emerged during the focus group discussions.

Results

Table 3 shows the themes discussed by the participants.

Sleep Attributes

Participants in nearly all of the focus groups described attributes of sleep, such as onset or falling asleep (8/10 groups), duration and timing of sleep (9/10 groups), continuity or staying asleep (9/10 groups), offset or waking in the morning (6/10 groups), and napping (10/10 groups). A main consideration with regard to napping was the demand of one's daily schedule. For example, several participants in active treatment observed that on a busy day they did not feel fatigued, but on a day off with nothing to do they collapsed and had to take a nap. Others described how being retired or on disability-related leave allowed them to nap whenever they felt tired, which made a lack of continuous nighttime sleep less bothersome.

Causes of Poor Sleep

Contributors to poor sleep were a prominent theme of the focus group discussions. Among the many symptoms participants described as causes of poor sleep, a major theme mentioned in all 10 groups was difficulty with temperature regulation, usually hot flashes or night sweats. As one participant in treatment for a hematological cancer described,

> My sleep was affected a great deal by night sweats. In fact, in a lot of ways, I think of that as being the worst part of it…. When I was told after my 3-month check that my bone marrow biopsy revealed some cancer still and that I may have to do other things associated with getting better again, all I could think about was if I was going to get those night sweats again. Those are really terrible. I would wake up sometimes 3 times a night… [with my] shirt completely soaking wet—it's just the worst. Sheets soaking wet, pillowcase wet. So that really affected my sleep.

Constraints on sleep positioning were mentioned frequently (7/10 groups). Problems with sleep positioning were related to medical devices (e.g., ostomies and ports as reported in the breast, colorectal, and other groups), surgical scars or radiation burns (reported in the breast group), and difficulty breathing (reported in the lung group). Two participants with lung cancer (1 in treatment, 1 in follow-up) described frustration with having to remain in an upright position and thus not being able to get comfortable enough to sleep well.

Worry or fear related to diagnosis, prognosis, or recurrence was another major theme (9/10 groups). Participants described being unable to fall asleep because of these concerns. One

participant said, “I think at the beginning it just haunted me, and I wasn't able to sleep at all. I was very worried and up all night.” Others found themselves waking repeatedly during the night, such as a participant with prostate cancer who said, “I would say that maybe once a week I’d wake up at 1:00 [a.m.] or 3:00 [a.m.], thinking, ‘I have cancer.’” A participant with lung cancer shared,

> I think it was more psychological, ‘cause I haven’t had to take any chemo or radiation so I don’t know what the effects of that would be. This psychological thing, once they tell you you’ve got cancer, it is like a death sentence. Your mind goes to playing tricks on you, and it is devastating, and it is hard to overcome.

Another component was worry related to upcoming doctor appointments and whether a recurrence would be discovered.

Changes in dreams (i.e., increased number, more vivid dreams, nightmares) were attributed to cancer or its treatments and blamed for disrupting sleep by participants in 6 of the 10 focus groups. Apnea and periodic limb movements were also discussed in 4 of the 10 groups. Two participants in treatment for breast cancer described problems with movement suggestive of restless leg syndrome. One said, “You have an urge to move. So when you are trying to go to sleep and you are always having an urge to move, you are not going to go to sleep.”

Daytime Functioning

Impairment in daytime functioning as a consequence of poor sleep was a universal theme. Daytime sleepiness was discussed in all 10 groups and fatigue (by name) in 9 of the 10 groups. The concepts overlapped for many participants, though not all. Some participants described daytime sleepiness and feeling tired. A participant in treatment for breast cancer said, “I find that I’m just being tired generally, even if I slept for 12 hours. I still wake up and I’m tired. I’m kind of sleepy all the time.” Other participants described impairment in daytime function as fatigue: “Fatigue is the big thing. I’m tired all the time…. I take naps during the day, you know, I just don’t have the energy not to take them.” A few participants distinguished fatigue from daytime sleepiness, linking fatigue with anemia, such as a participant with breast cancer who said, “I find fatigue and sleepiness are different. I don’t find them to be the same. I can sleep all I want and still be fatigued because my red blood cells were down.”

Other types of daytime impairment, including social, functional, and mood-related consequences of poor sleep, were also mentioned frequently (7 of 10 groups). For example, some participants had to become more flexible with their social engagements, such as a participant in treatment for breast cancer who said, “I find that I have to cancel things a lot or rearrange my schedule…because I’m too tired or I sleep too late.” Changes in relationships with friends and family were also described, “we go to visit friends, and sometimes I’ll sit in the chair and go to sleep, so I think it’s made a big change in relationships.”

Changes in the capacity for activities that involve sustained mental concentration, such as driving and working, were also identified as themes of altered sleep-wake functioning. One participant in treatment for colorectal cancer said, “When I take that pain medication, I could be sitting at a stop light and go to sleep.” Problems with work were mentioned. A participant in treatment for breast cancer said, “Ativan [lorazepam, a sedative] almost got me fired though. Because I finally took it about 3:00 [a.m.]… then at 3:00 p.m., I’m waking up. I’m like, ‘Oh, my God. I haven’t called work.’”

Finally, mood disturbance as a result of altered sleep-wake functioning was another theme. One participant in posttreatment follow-up said she gets "pouty" after inadequate sleep. She asked, "Does anyone else get pouty if you only get 3 or 4 hours?" Another participant responded, "I get crabby," and a third said, "I think my judgments aren't as good."

Other Themes

Other themes included beliefs about sleep, variations in sleep problems related to particular treatment cycles, the persistence of sleep problems after treatment has ended, and managing problems with sleep.

Belief in the importance of sleep in controlling cancer and recovery from treatment was common (9/10 groups). A participant in treatment for lung cancer described sleep as important because "if you're not getting your rest, your body's going to be more and more run down, the more run down your body is, the more disease is going to be able to function and root." A participant with breast cancer said, "You have to find some way to make us sleep so that we can heal…. You probably won't beat the disease unless you get the required amount of sleep."

Many participants in treatment discussed variations in sleep problems related to their treatments. Participants undergoing chemotherapy reported that their sleep cycle and energy level followed a pattern that varied with the chemotherapy cycle, such as a cycle of hypersomnia and then insomnia after chemotherapy. Patients reported being unable to sleep while taking steroids. Night sweats, hot flashes, and vivid dreams were attributed to medications by some (e.g., participants on hormonal therapy for breast or prostate cancer). Patients with breast cancer who were treated with aromatase inhibitors and those treated for anemia or neutropenia reported difficulty falling asleep due to joint, muscle, or bone pain and waking with pain.

Participants reported that sleep problems at diagnosis and during treatment made it difficult to maintain a healthy sleep cycle, which leads to later sleep difficulties. Although sleep returned to normal for many after treatment, others found that sleep problems did not go away. They reported needing more sleep, napping more, having greater difficulty if sleep was missed, having more disrupted sleep, and experiencing more vivid dreams since treatment. One patient said, "I have not, since diagnosis, slept—not like I did prior to, even without the chemo." Another said, "I still probably, after years off [treatment], sleep about an hour or 2 more than I used to." Participants also discussed difficulty reading body signals, making it more difficult to know when rest is needed. Even after being "cancer-free," participants reported sleep disturbances related to emotions and thoughts prior to follow-up tests, before doctor appointments, after experiencing a new unexplained physical symptom, and when hearing or thinking about a friend or family member with cancer. As one participant described,

> But on the nights that I wake up, or I can't get back to sleep, my mind just—it starts rolling. And the more it rolls, the more I'm convinced that the reason I can't sleep is because cancer is coming back, and so I have to just—I have to find some way to shut off my mind, because the more I think about it, the more I'm convinced that, you know, it's coming back.

Discussions of ways to manage sleep problems were frequent and included prescription medications (7/10 groups), over-the-counter medications (2/10 groups), and other strategies (9/10 groups), such as watching television, daily exercise, dietary adjustments (e.g., low sodium), reading, prayer or meditation, making a list before bed of what needs to be done the next day, or using special pillows to aid sleep positioning.

Discussion

Despite the prevalence and persistence of sleep difficulties among people diagnosed with cancer, only one other study has used qualitative methods to examine the specific aspects of the cancer experience that may cause sleep-wake disturbances or the impact of these disturbances on quality of life. Our study used focus groups to provide the most comprehensive qualitative examination to date of the unique ways sleep is disturbed by cancer and its treatments.

Participants described a number of specific factors related to disturbed sleep. These included abnormal dreams, symptoms suggestive of restless legs syndrome and neuropathy, night sweats, problems with positioning due to discomfort or devices related to cancer treatment, and worry about disease or prognosis. Although restless legs syndrome and pain are causes of disturbed sleep associated with chronic insomnia [28], including insomnia comorbid with cancer [29], other features of sleep disturbance such as abnormal dreams, anxiety about the implications of a cancer diagnosis, night sweats, and positioning problems have had little empirical documentation and may be unique to this population.

Impairments in daytime function described by some participants included excessive daytime sleepiness, falling asleep unintentionally, fatigue, and irritability. These experiences contrast with the experiences of nonelderly patients with insomnia, for whom fatigue and tiredness are reported during the day but falling asleep unintentionally does not typically occur [30]. The fact that excessive daytime sleepiness, tiredness, and fatigue are all reported by patients with cancer suggests that self-reported measures of sleep-wake function in this population will need to employ specific assessments aimed at differentiating the related feelings of fatigue and tiredness from unintentional sleep episodes. It also seems clear that patients may not fully distinguish between fatigue and tiredness. We did not explicitly ask participants to make this distinction, and this should be a topic of future qualitative inquiry.

Many participants expressed concerns about the importance of sleep for fighting cancer. Participants were often distressed about the potential negative impact that sleep difficulties could have on their health and their response to treatment and feared that they would contribute to a higher risk of cancer recurrence or progression. These patients experienced worry or concern that chronic insomnia would threaten their health and their ability to fight cancer. Indeed, some evidence suggests that sleep-wake function may be important for immune defense against tumor cells [1], and there is some support for a causal relationship between clinical insomnia and immune functioning [31]. Psychosocial distress related to worry about the effects of poor sleep is a significant health concern in its own right, especially given the reciprocal relationship between anxiety about sleep and sleep quality. This concern was also noted in a small focus group study (n = 6) of individuals undergoing cognitive-behavioral treatment for insomnia [32], Cancer diagnosis may represent an important opportunity for patient education, in that patients' motivation is high to address what may be a lifelong difficulties with sleep quality and poor sleep habits.

The extent to which commonly used self-reported measures of sleep quality capture the full spectrum of sleep-wake disturbance that accompanies the cancer experience has undergone little empirical study. Our findings and those of other investigators [21] suggest that symptom distress is an important covariate of impaired sleep quality for patients with cancer and should be evaluated in conjunction with measures of sleep. Thus, in addition to capturing fundamental attributes of function, including sleep onset, duration and timing, continuity, offset, napping, and daytime function, adequate measures of sleep-wake functioning for patients with cancer should include causes of poor sleep such as abnormal dreams, anxiety about the implications of cancer diagnosis, night sweats, and positioning

problems. Self-report measures should also employ the terminology patients use to describe their problems. For example, the use of the word “insomnia” was infrequent during these groups, fatigue and tiredness were not typically distinguished; and many patients confused night sweats with hot flashes.

The findings of this study have implications for clinicians by demonstrating that it is important to assess patients for a wide range of sleep-wake difficulties. Of most importance is to screen patients for disturbed sleep and daytime sleepiness. If sleep disturbance is identified, behavioral, psychological, or pharmacological treatments should be discussed. There is a growing body of literature addressing the effectiveness of treatments for fatigue [33–35]; however, less evidence is available to guide the management of insomnia in patients with cancer, though these patients may have preferences for treatment of their sleep problems [36]. Few trials have examined both sleep quality and fatigue outcomes simultaneously [37]. Studies of the comparative effectiveness of interventions that have shown promise in addressing chronic insomnia in other patient populations would also be useful in cancer populations to establish the basis for rational treatment selection. Our study underscores the multifaceted nature of sleep-wake difficulties in cancer and provides direction for the development of outcome measures that are tailored to capture the full scope and complexity of these difficulties and their consequences for patients with cancer.

Acknowledgments

This work was supported by a National Cancer Institute supplement to grant U01AR052186 from the National Institutes of Health.

The authors thank Amy P. Abernethy of Duke University, Daniel J. Buysse of the University of Pittsburgh, and Nan Rothrock of the NorthShore University HealthSystem for participation in the PROMIS Sleep-Wake Function Domain Committee; and Damon M. Seils of Duke University for assistance with manuscript preparation.

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Table 1

Participant Characteristics (N = 67)

Characteristic	No. (%)
Age, y	
< 40	5 (7)
41 to 50	15 (22)
51 to 64	28 (42)
65 to 79	14 (21)
≥ 80	5 (7)
Sex	
Female	24 (26)
Male	43 (64)
Race	
Black or African American	20 (30)
White	47 (70)
Ethnicity[a]	
Hispanic or Latino	64 (96)
Not Hispanic or Latino	1 (1)
Missing	2 (3)
Continuum of care	
Active treatment, early stage	17 (25)
Active treatment, advanced stage	22 (33)
Active treatment, unknown stage	9 (13)
Treatment completed < 5 years after diagnosis	11 (16)
Treatment completed ≥ 5 years after diagnosis	8 (12)
Cancer site	
Brain	1 (1)
Breast	12 (18)
Colorectal	3 (4)
Gynecologic	5 (7)
Hematologic	10 (15)
Lung	5 (7)
Other gastrointestinal	3 (4)
Prostate	18 (27)
Other	10 (15)

[a]The variable was missing for 2 participants.

Table 2

Sample of Focus Group Questions

Scope and Importance	
1	In your experience, what are some of the ways cancer and its treatments have affected your sleep?
2	How important a topic is this in relation to other issues in your life?
3	How much do problems sleeping affect overall quality-of-life?
Impact of Cancer on Sleep	
4	How do the physical symptoms of cancer interfere with sleep?
5	How do emotions related to cancer or its treatments affect sleep?
Impact of Sleep Difficulties on Quality of Life	
6	Do problems sleeping make other physical symptoms worse? If yes, in what ways?
7	Do problems sleeping affect you psychologically, that is, do they change the way you feel or think?
8	What are some of the ways in which problems sleeping have affected your social life or relationships?
Managing Sleep Difficulties	
9	How do you cope or manage the issues with sleep that we have discussed?

Table 3

Themes Discussed During Focus Groups, Overall and By Group (N = 67)

Theme	Total[b]	Active Treatment (7 Groups)[a]						Completed Treatment (3 Groups)			
		Breast (n = 8)	Prostate (n = 3)	Prostate (n = 9)	Lung (n = 4)	Hematological (n = 4)	Colorectal (n = 4)	Other (n = 7)	Other (n = 9)	Other (n = 10)	Other (n = 9)
Sleep attributes											
Onset	8	•		•	•	•	•	•		•	•
Duration and timing	9	•		•	•	•	•	•	•	•	•
Continuity	9	•	•		•	•	•	•	•	•	•
Offset (waking in the morning)	6			•		•	•	•	•	•	
Napping	10	•	•	•	•	•	•	•	•	•	•
Causes of poor sleep											
Sleep disorders											
Dreams	6	•			•	•	•	•			•
Apnea	4			•	•		•	•			
Movement	4	•	•		•						•
Parasomnia	1						•				
Environmental factors											
Bed partner	2						•	•			
Physical factors											
Bowel control or urination	4	•	•	•		•					
Pain	6	•			•		•	•	•		•
Nausea	1									•	
Hot flashes, night sweats, or temperature regulation	10	•	•	•	•	•	•	•	•	•	•
Positioning	7	•			•		•	•	•	•	•
Difficulty breathing	1							•			
Numbness	2								•		•
Muscle cramps	2						•				•
Ostomy	1	•									
Radiation burns	1	•									
Restless legs	6	•	•		•		•		•		•

Theme	Total[b]	Active Treatment (7 Groups)[a]					Completed Treatment (3 Groups)			
		Breast (n = 8)	Prostate (n = 3)	Prostate (n = 9)	Lung (n = 4)	Hematological (n = 4)	Colorectal (n = 4)	Other (n = 7)	Other (n = 9)	Other (n = 10)	Other (n = 9)
Cognitive factors											
Worry or fear	9	•		•	•	•	•	•	•	•	•
Daytime function											
Sleepiness/tiredness	10	•	•	•	•	•	•	•	•	•	•
Fatigue	9	•		•	•	•	•	•	•	•	•
Consequences of poor sleep	7	•				•	•	•	•	•	•
Beliefs	9	•		•	•	•	•	•	•	•	•
Managing sleep problems	6										
Over-the-counter sleep aids	2	•			•						
Prescription sleep aids	7	•		•	•	•	•	•			•
Other strategies	9	•	•	•	•	•	•		•	•	•
Insomnia	2									•	•

[a] During or before active treatment for cancer.

[b] Number of groups out of 10 that discussed the theme.