Patient and Clinician Communication Of Self-Reported Insomnia During Ambulatory Cancer Care Clinic Visits

Dr. Mary Lou Siefert, DNSc, RN, AOCN, **Dr. Fangxin Hong, PhD**, **Ms. Bianca Valcarce**, and **Dr. Donna L. Berry, PhD, RN, AOCN, FAAN**

The Phyllis F. Cantor Center for Research in Nursing and Patient Care Services (Drs Siefert and Berry, and Ms. Valcarce); and Department of Biostatistics and Computational Biology (Dr. Hong), Dana Farber Cancer Institute, Boston, MA

Abstract

Background—Insomnia, the most commonly reported sleep wake disturbance in people with cancer, has an adverse affect on quality of life including emotional well being, distress associated with other symptoms, daily functioning, relationships and ability to work.

Objective—The aim of this study was to describe the content of discussions between clinicians and 120 patients with self-reported insomnia and to examine the associations of socio-demographic, clinical and environmental factors with insomnia.

Interventions/Methods—A secondary analysis was conducted with self reported symptom data, socio- demographic, clinical and environmental factors. Recordings of clinician and patient discussions during clinic visits were examined by conducting a content analysis.

Results—Severe insomnia was more likely to be reported by women, minority and lower income individuals. Seven major topics were identified in the discussions. The clinicians did *not* always discuss insomnia; discussion rates differed by diagnosis and clinical service.

Conclusions—Reporting of insomnia by the patient and clinician communication about insomnia may have differed by demographic and clinical characteristics. Clinicians attended to insomnia about half the time with management strategies likely to be effective. Explanations may be that insomnia had a low clinician priority for the clinic visit or lack of clear evidence to support insomnia interventions.

Implications for Practice—A better understanding is needed about why insomnia is not addressed even when reported by patients; it is well known that structured assessments and early interventions can improve quality of life. Research is warranted to better understand potential disparities in cancer care.

Background

Sleep-wake disturbances are frequently experienced by people with cancer and often are associated with the stress of a cancer diagnosis, other distressing symptoms such as pain, depression, anxiety, plus multiple bio-physiological factors.[1,2] Various methods have been utilized to assess insomnia, the most common sleep-wake disturbance, along with other cancer-specific symptoms; self-report of such experiences has been incorporated in research and clinical practice.[3]

Correspondence: Mary Lou Siefert, DNSc, RN, AOCN; Dana Farber Cancer Institute, 450 Brookline Avenue; LW515; Boston, MA 02215 (mlsiefet@aya.yale.edu or maryl_siefert@dfci.harvard.edu).

From 2004 to 2007, the Electronic Self-Report Assessment-Cancer (ESRA-C) study was conducted at the Seattle Cancer Care Alliance.[4] The ESRA-C randomized clinical trial was designed to compare discussion rates of symptoms and quality of life issues (SQLI) between an intervention group, in which the ESRA-C summary report of SQLI was available to the clinical team, and a control group, in which the ESRA-C summary report was not available. In this secondary analysis of trial data, we report the nature of and who initiated clinic visit discussions regarding insomnia between oncology clinicians and patients who reported problems with falling asleep and staying asleep.

Insomnia in the patient with cancer

Insomnia is generally described as a sleep-wake disturbance in which one has difficulty or the inability to fall asleep and or difficulty remaining asleep for a reasonable amount of time. In the DSM-IV insomnia is defined by the American Psychiatric Association[5] (as cited in) as difficulty initiating or maintaining sleep, or non restorative sleep, for at least one month and causes distress in important areas of functioning.[5,6] Insomnia is much more prevalent in people with cancer than the general population. It is estimated that about 50% people with cancer experience insomnia versus 10%–15% in the general population.[7] It is the most common sleep wake disturbance in people with cancer[7,8], and is associated with cognitive dysfunction, changes in the ability to work, a decline in quality of life, and alterations to bodily functions, thus requiring attention and intervention from the oncology provider.[9] Despite evidence indicating the prevalence and distress associated with all sleep wake disturbances, assessment of the disturbances is not optimum; clinicians ask about sleep less than 50% of the time, and performed a comprehensive sleep assessment even less frequently.[10]

Two of five themes that emerged from a qualitative study of patients with cancer and sleep problems specified the need for the oncology clinician to recognize the importance of sleep and thereby ask the patient about it, and that the assessment of sleep needs to be incorporated into the usual care. Other themes identified were that sleep is important, patients lack information about sleep and its relationship to cancer and its treatments, and that patients did not think it was appropriate to bring sleep problems to the attention of the oncology clinician.[11]

These findings support the importance of assessing and treating insomnia, a distressing and prevalent problem for people with cancer. Despite the prevalence and importance given to sleep, insomnia is not routinely discussed during oncology appointments. Patients with cancer may not think it is appropriate to volunteer information about their sleep problems during oncology appointments and health care professionals may not routinely assess and treat insomnia.

Insomnia and quality of life

Sleep wake disturbances and specifically insomnia are associated with adverse quality of life in both men and women with cancer at the time of diagnosis, during treatment and post treatment.[12–15] In a study with 263 people with cancer who were receiving chemotherapy, Redeker et al.[15] reported that insomnia, fatigue, depression, and anxiety were all associated with each other and with an adverse quality of life. However, the researchers reported that fatigue and insomnia only explained a very small portion of the variance in the negative effect on quality of life and that depression explained a much larger variance[15]. Insomnia and fatigue were related to depression and depression is known to be closely associated with diminished quality of life. Broeckel and colleagues[16], Kim, Lee and Lee[17] and Dow and colleagues[18] found that even following treatment, breast cancer survivors continued to have problems with sleep which were associated with other symptoms and adverse quality of life.

Arndt and colleagues[19] reported worse quality of life and insomnia in younger colon cancer survivors when compared to the general population and in a qualitative study of 21 cancer survivors, Fleming and colleagues[13] found that the adverse effect of insomnia on quality of life lasted well beyond the cessation of active treatment for cancer. In another qualitative study[20] women with breast cancer reported that the presence of physical symptoms including insomnia adversely affected their emotional well being which adversely affected their "strength to commit themselves to treatment".[20](p.735)

Insomnia in people with cancer has an adverse affect on many areas of quality of life including emotional well being, distress associated with other symptoms, daily functioning, relationships and the ability to work.[20–23]

The quality of life for individuals with cancer is adversely affected by insomnia along the entire trajectory of cancer, and notably well beyond the treatment phase. Insomnia may have a larger impact on adverse quality of life in younger people than in older people. [19,23] The association of insomnia with other distressful symptoms such as depression and fatigue is well supported in the literature and in combination, these symptoms have an even greater adverse effect on quality of life in people with cancer.[13,20–22,24] Given the adverse affect on quality of life, exploration on clinical assessment and treatment of insomnia in people with cancer is warranted.

Framework

Insomnia is a complex phenomenon that needs to be more clearly understood in order to address it effectively. A better understanding of the various patient, system and illness related factors that may affect insomnia and the treatment of it is needed by nurses and other clinicians caring for people with cancer in order to assess and treat insomnia effectively. The authors of this study posited that because independent, interventions alone do not consistently affect patient outcomes, a model that considers multiple influences (or mediators) is necessary.

The Oncology Nursing Society's position paper on Quality Cancer Care [25] stated that quality care across the illness continuum includes "comprehensive symptom management, including physical and psychosocial care" provided by "professional nurses who are competent in the essentials of oncology nursing care" and who collaborate with other disciplines; and that patients and their families have the right to "… timely and appropriate management of the physical, psychosocial, cultural, and spiritual needs". An integrated approach to such patient care is presented in the human response framework[26], a heuristic developed to explain nurses' practice which neither isolates the disease condition or a particular symptom as the only focus nor does it ignore the contributing factors which modify a patient's responses. This framework illustrates the complex nature of individual responses to the cancer experience, highlighting the influence of person and environmental factors on the human responses to cancer including physiological, experiential and cognitive/behavioral responses. Cancer clinicians, particularly nurses whose practice often incorporates integrated and holistic care, face the challenging task of assessing and treating cancer and associated symptoms in the context of each patient's individual life.

However, the context of the patient's life is not the only relevant consideration in a cancer care setting. The system of cancer care certainly can influence the outcome of practically every intervention delivered. This understanding was explicated in the Quality Health Outcomes Model developed by the American Academy of Nursing Expert Panel on Quality Health Care[27] which guided the larger ESRA-C study. In a clinical setting, all patient outcomes have been mediated by some aspect(s) of the system and/or some patient aspect(s).

Purpose

The purpose of this secondary analysis was to describe the content of the conversations between clinicians and patients with self-reported insomnia during clinic visits and to examine the associations of socio-demographic, clinical and environmental factors with self-reported insomnia.

Methods

Design

This study is a secondary analysis of data consisting of self reported symptoms, socio-demographic, clinical and environmental factors. A content analysis was also conducted with recordings of clinician and patient discussions during oncology clinic visits.

Sample

In the original study, [4] 660 ambulatory patients were randomized to either the intervention or control group after self-reporting SQLI a second time (T2) approximately 6 weeks after beginning cancer therapy. The ESRA-C assessment included the Symptom Distress Scale (SDS). [28,29] For the patients in the intervention group, the clinicians received summaries of the ESRA-C SQLI reports just prior to the T2 face-to-face clinic visits. The discussions between the participants and clinicians during the T2 visits were audio-recorded and later de-identified. Nearly all 660 participants (n=654; 99%) responded to the insomnia item of the SDS at T2. Of the 654 participants, 20.6% (n=135) reported high levels of insomnia distress, a 4 or 5 (out of 5) response to the insomnia item on the SDS. Audible clinic visit recordings existed for 120 of these 135 participants and comprised the sample for this analysis.

Measurement

The Symptom Distress Scale (SDS) is a 13-item self-report scale assessing the frequency or distress related to 11 different cancer-related symptoms, one of which is insomnia.[28,29] Reliability and validity are widely reported for the SDS and the scale has been utilized to establish validity for other instruments assessing symptoms among cancer patients.[30,31] Each item is rated by the patient on a five point Likert type scale (range 1–5); 1 represents the least distress or frequency and 5 is the highest frequency or worst distress associated with a particular symptom. The unweighted item scores are summed to obtain a total Symptom Distress score that can range from 13–65.[30] A moderate to high score (3, 4, or 5) for any one symptom should alert the researcher or clinician of the need for an appropriate clinical assessment and determination of appropriate interventions (personal communication, R. McCorkle, 3/23/12). Descriptive statements operationalize each response point. For insomnia, a response of 1 indicates that sleep is no different than usual and a 5 indicates the most distress related to insomnia. For the purposes of this analysis, a response of either 4 or 5 to the insomnia item on the SDS was defined as severe insomnia representing a high frequency of and distress related to insomnia. Specifically, following the SDS manual[30] a response of 4 read: *I have difficulty getting to sleep or staying asleep almost every night* and a response of 5 read: *It is almost impossible for me to get a decent night's sleep.*

Analysis

The 120 audio recordings were examined for whether or not insomnia was mentioned at all resulting in 78 cases in which insomnia was reported as a 4 or 5 on the SDS and there was an audible recording of the discussion of insomnia between the clinician and the participant. All discussions relevant to insomnia were transcribed verbatim.

A content analysis was performed on the transcript to explore the nature of the discussions between the participants and the clinicians and the subsequent clinician recommendations related to insomnia. The content related to insomnia was categorized by the topics discussed during the visit. The audio data were categorized originally by one author, BV, under the guidance of the study's principal investigator (DB). Following the original categorization, a second author (MLS) independently performed confirmatory coding. The original categorization was reviewed by MLS by listening to the audio recordings and reviewing the transcript data and subsequent original coding related to the insomnia discussions in all 78 audio recordings. Questions about the original coding categorization arose in 15 of the 78 (19%) transcripts of the audio recordings. Changes in the coding categorization was proposed by MLS for 13 of the 15 audio recordings; MLS and DB discussed the proposed changes for the 13 audio recordings and achieved consensus on the final categorizations.

The 135 participants who reported insomnia were compared with the rest of the original study sample (N=654) for any significance differences in baseline socio-demographic and/or clinical and environmental characteristics. The 15 participants who had no, or inaudible, audio recordings were excluded from the subsequent analysis under the assumption of missing-at-random. The assumption was validated by checking baseline characteristics with the remaining 120 participants.

Associations were then explored between socio-demographic, clinical and environmental factors and the 1) report of severe insomnia, 2) discussion of insomnia, and 3) topics identified in the content analysis of the recordings. Socio-demographic factors included the participant's gender, race, education, marital status, income, and computer use. The clinical and environmental factors selected included: study group (intervention/control) from the original study, clinical service, provider gender and participant's diagnosis. Three clinical services: medical oncology, radiation oncology and stem cell transplant and the following cancer diagnoses were included: breast, gastrointestinal, genitourinary, gynecologic, head and neck, leukemia, lung, lymphoma and myeloma (Table 1).

Associations between variables were tested with Fisher exact or Chi-square tests for the categorical variables and Wilcoxon rank-sum test for continuous variables. A negligible percent (2–8%) of participants had missing data for a few socio-demographic factors (education, income and computer use), and were excluded from the tests of association. A two-sided p-value of 0.05 was used as the significance level for all tests. Due to the limited sample size and the exploratory nature of the analysis, multiple comparison adjustments were not performed. All analysis was performed using SAS (version 9.2)

Results

Baseline socio-demographic, clinical and environmental characteristics are provided in Table 2 for the total sample (N=654), 135 participants with severe insomnia (scores of 4 or 5) versus the 519 participants with mild or no insomnia (scores 3). There was a significant association (p=0.02) between participant gender and absence/presence of severe insomnia, suggesting that women were more likely to report severe insomnia than men. Marginal associations were observed between participants with and without severe insomnia for race (p=0.06), income (p=0.06), and frequent computer use (p=0.09), suggesting a trend that minority race participants and those with lower incomes were more likely to report a severe insomnia problem while those who reported frequent computer use trended toward mild/no insomnia. There were no significant differences between the participants with or without severe insomnia by clinical service or cancer diagnosis. There were no significant differences in socio-demographic and clinical or environmental factors between the 15

participants without audio-recorded data and the 120 with the audio recorded data; therefore we performed the analysis on the 120 participants with audio recordings.

Table 3 depicts whether the insomnia was discussed or not in the clinic visit and the characteristics of the 120 participants with audible clinic visit recordings. Insomnia was discussed during consultation with 78 of 120 (65%) participants.

There was a significant association between the likelihood of discussing insomnia and clinical service (p=0.002), frequent computer use (p=0.03) and diagnosis (p=0.03), suggesting that insomnia was more likely to be discussed during the medical oncology or transplant visits, with frequent computer users and participants with genitourinary cancer, gynecological cancer, head and neck cancer or leukemia.

Seven topics covered during the participant and clinician discussions (Table 4) were identified in the content analysis. Interventions to address the insomnia discussed in the 78 visits were categorized as pharmacological (n=39, 50%) and non-pharmacological (n=10, 13%). Concomitant symptoms (e.g., pain) were addressed in 36 (46%) visits plus discussion of external factors contributing to sleep problems (noisy environment) was noted in 10 visits (13%). Clinicians changed the subject away from insomnia in 15 visits (19%). The fact that sleep had improved was evident in 9 (12%) recordings. Clinicians verbalized specific recommendations to monitor and follow insomnia over the near future in 4 visits (5%). Due to the limited sample size, the associations were explored only for the most frequently occurring topics, pharmacological interventions, a change of subject and the presence of concomitant symptoms (data not shown).

Income (p= 0.02), and diagnosis (p=0.017) were significantly associated with pharmacologic interventions, suggesting that participants with higher incomes, breast or gastrointestinal cancer were more likely to receive pharmacologic interventions compared with participants with lower incomes, head and neck cancer or myeloma. Clinician change of subject away from insomnia was significantly more likely with the 5 minority participants There were no differences in the group where the subject was changed between minority and non minority participants by gender, education, marital status, income, computer use or cancer diagnosis. Almost half (46.2%) of all participants with severe insomnia verbally reported concomitant symptoms during the clinic visit. No significant associations were identified between concomitant symptoms and socio-demographic, clinical and environmental factors.

Discussion

Insomnia was prevalent in this sample of ambulatory patients with cancer; this was not surprising as insomnia rates are high in people with cancer.[32] Women reported severe insomnia more frequently than men; there was no difference by age. The recommendations made to patients regarding management of insomnia varied widely and included medications, lifestyle changes, and sometimes nothing. Despite receiving printed summaries of patient-reported SQLI indicating problems with insomnia in half the sample, the clinicians did *not* always discuss insomnia during the visit. The radiation oncology clinicians discussed the sleep problems less frequently than the other clinicians. Perhaps this can be explained by the typical short visit time allotted in that department for weekly clinician visits. However, the lack of discussion and further assessment by clinicians in radiation oncology is important to note since a better understanding of fatigue in people receiving radiation therapy has received attention recently.[33,34] Fatigue is common in this population and is associated with other symptoms including insomnia and physiological changes which, if addressed, may result in better sleep and less fatigue.[13,35,36]

It is not clear from the audio recordings why, even when provided with printed summaries of the ESRA-C SQLI *or* when patients brought up the topic of sleep problems, oncology clinicians did not address the problem with many of the patients or why the subject was changed. It is possible that the clinicians did not review the printed summaries, or did not wish to address the sleep problems. Another possible explanation is that insomnia was a lower clinician priority for that particular clinic visit. The results of the larger trial[4] did document a large range of discussion frequency among SQLI in which, for example, nausea and pain were almost always discussed and the impact of the cancer on sexual activities was rarely discussed. And in the group where the subject was changed by the clinician, there were no clear socio-demographic or clinical differences between the minority and non minority patients.

This data set and analysis have a few limitations. A secondary analysis of data, despite the efficiency of its use, has limitations related to lack of control over the original data.[37,38] However, the controls that were implemented when the data were gathered are fully described in the original study[4], and the findings can be generalized with confidence to a similar population of patients; in this case, fairly well-educated white patients treated at a comprehensive cancer center.

The sample was a selected subset of patients described previously in the sample section who reported severe insomnia in order to focus the evaluation of the clinic visit conversation for this study. The relatively small sample size of 120 cases limited the power to fully test potential associated factors. Yet, the results are informative for a future large, prospective trial in which interventions specific to sleep-wake disturbances are incorporated.

We found that it was more likely that women reported severe insomnia. The review conducted by Palesh et al.[32] did not find a difference in rates of insomnia based on gender. Women with breast cancer do report insomnia and fatigue as prevalent and distressing symptoms.[39,40] In a large study of over 8500 people in Great Britain, Arber and colleagues[41] reported relationships between socio-economic differences and reported sleep problems. The researchers found that more women reported sleep problems than men, and reported that a significant relationship was found with age for women but not for men. When Arber and colleagues fully adjusted for all socio-economic and other variables, significant relationships remained between sleep problems and employment status and education level Sleep problems may not be associated simply with gender, but rather the issue may be confounded with other factors such as hormonal status and socio-economic status.[41–43]

We found that for the patients who reported frequent computer use there was a greater likelihood of discussion of the insomnia symptom than with other patients. This was the only socio-demographic factor associated with the likelihood of the discussion and may be a proxy for a level of patient sophistication with communication, thus prompting or pursuing the provider's assessment and discussion. There was no difference in whether the problem was assessed by the clinician during the discussions based on type of cancer. The sample was not racially diverse; however, it does represent the population from which the sample was drawn in western Washington State. Future replication of the study in minority and different socio-economic strata is warranted to better understand these factors.

Finally, it is also possible that the Hawthorne effect was introduced by the recording of the discussions between the providers and patients and families and thus may have affected the behavior of those being recorded.[44] However, it is virtually impossible to obtain the richness and depth of discussions such as those reported in this study without recording the dialogue.

Implications

Although it is recommended that one should address symptoms that may interfere with sleep such as pain, the evidence for the treatment of sleep problems may not be clear. Strong evidence is limited to various behavioral, pharmacologic and interventions individually or in combination with each other and any there is no strong basis to recommend one intervention over another. Page, Berger and Johnson[45] conducted searches using the major search engines (MEDLINE®, CINAHL®, and PsychINFO) and reviewed all pharmacological and non-pharmacological intervention studies examining sleep in adults with cancer. After reviewing the intervention studies none of the pharmacological, complementary or cognitive behavioral therapies (CBTs) that were used for sleep problems were recommended[45]. In another review conducted by Dy and Apostol,[12] pharmacologic interventions showed no benefit over CBT for people with advanced cancer. Others have reported that cognitive behavior therapy, may have some benefit[8,46] independent of demographic or clinical characteristics, and combined with pharmacologic interventions may provide the best therapeutic approach for insomnia. Espie and colleagues [44] conducted a randomized controlled trial of 150 patients with cancer; those who received the CBT reported improved sleep patterns, and quality of life.

Patients should receive appropriate treatment that is individualized and considers socioeconomic, and clinical factors.[6] The lack of strong evidence and clear guidelines supporting specific interventions for the treatment of sleep problems in people with cancer may contribute to clinicians' hesitancy to address this problem; the uncertainty regarding the effectiveness of interventions and how to best use them may contribute to a lack of assessment in the first place. However, it is important for all oncology clinicians to conduct a structured symptom assessment and address symptoms and the related distress reported by patients as a first step to maximize QOL.

Conducting a structured assessment has resulted in a larger number of reported symptoms versus asking the patient opened ended questions.[47] Patients may be reluctant to report sleep problems[11] and providing a summary report for the clinicians results in an overall increase in the discussion of SQLI.[4] A decrease in distress over time[48] and overall improved QOL may be improved with structured assessments of symptoms.[49,50]

Insomnia is a distressful symptom that is prevalent in people with cancer and is associated with other distressing symptoms, thus having a negative impact on one's QOL. It is therefore, also important to treat insomnia as well as other symptoms with evidence-based interventions. We recommend a thorough assessment of symptoms by oncology clinicians and the use of evidence based interventions to assist patients with insomnia and to improve their quality of life. Future research should also seek to better understand the effect of interventions for insomnia, why clinicians are not addressing this problem, and the development of evidence based intervention guidelines.

It is important for oncology nurses and other clinicians to recognize the prevalence of insomnia in people with cancer, its impact on one's quality of life, and the importance of symptom assessment and the use of evidence-based interventions to address this symptom. In addition to implementing early assessments of sleep problems, there are evidence based suggestions from the Oncology Nursing Society and reported in the literature.[45] Insomnia is a nursing-sensitive patient outcome; it is important that the assessment and treatment of insomnia become a priority of oncology nursing care.[51] The assessment should occur early in the disease and treatment trajectories and continue through survivorship. Education of oncology nurses should emphasize the importance of assessments that include directly asking patients about their sleep quality and the need to intervene for sleep problems.

Furthermore, it is essential to communicate assessment findings with other clinicians involved with the patient's care and/or in consultation and referral in order to promote improved QOL and outcomes for people with cancer.

Conclusion

Serious insomnia was a common issue for patients undergoing various types of cancer treatment in our trial. Concomitant, related symptoms were prevalent as well. While clinicians attended to these issues about half the time with management strategies likely to be effective, we found suggestions that women reported insomnia more often, and communication about insomnia with racial minority patients, those who used computers infrequently, and in radiation oncology clinic visits may have been incomplete. Patient income may have dictated whether or not pharmacologic strategies were recommended. These findings provide impetus for further study, addressing potential disparities in cancer care.

Acknowledgments

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Table 1

Definitions of Factors Used in Analysis of Associations

Socio-Demographic Factors	Clinical Factors	Environmental Factors	Insomnia Factors
Gender	Study Group	Clinical Service	Severe insomnia
Race	• Intervention	• Medical oncology	• Insomnia reported on SDS as 4 or 5
Education	• Control	• Radiation oncology	Insomnia discussed during visit
Marital Status	Diagnosis	• Stem cell transplant	• Yes or No
Income	• Breast	Provider Gender	Topics identified in content analysis
Computer Use	Gastrointestinal		• Pharmacological interventions
	• Genitourinary		• Concomitant symptoms
	• Gynecologic		• A change of subject
	• Head & Neck		
	• Leukemia		
	• Lung		
	• Lymphoma		
	• Myeloma		

Table 2

Sample Description by Severity of Insomnia in 654 Participants

Patient Characteristics	Insomnia Item Score[a]			
Socio-Demographic Factors	Total N=654 (100%)	High Score (4) n=135 (100%)	Low Score (3) n=519 (100%)	p-value[b]
Gender, male	351 (53.7%)	60 (44.4%)	291 (56.1%)	.02
Age, mean (range)	53.9 (18–89)	53.1 (24–84)	54.0 (18–89)	.50
Ethnicity, Hispanic/Latino	12 (1.8%)	3 (2.2%)	9 (1.7%)	.72
Race, minority or multiple[c]	48 (7.3%)	15 (11.1%)	33 (6.4%)	.06
Married/partnered	454 (69.4%)	89 (65.9%)	365 (70.3%)	.40
Low income (<35k HH annual)	153 (23.4%)	40 (29.6%)	113 (21.8%)	.06
Some college/college graduate	469 (71.7%)	92 (68.1%)	377 (72.6%)	.39
Frequent computer use	520 (79.5%)	100 (74.1%)	420 (80.9%)	.09
Study Group				.77
Control	330 (50.5%)	70 (51.9%)	260 (50.1%)	
Intervention	324 (49.5%)	65 (48.1%)	259 (49.9%)	
Clinical Factors				
Service line				.10
Medical	304 (46.5%)	55 (40.7%)	249 (48%)	
Radiation	152 (23.2%)	32 (23.7%)	120 (23.1%)	
Transplant	198 (30.3%)	48 (35.6%)	120 (28.9%)	
Cancer Diagnosis				.26
Breast	43 (6.6%)	11 (8.1%)	32 (6.2%)	
Gastrointestinal	78 (11.9%)	10 (7.4%)	68 (13.1%)	
Genitourinary	75 (11.5%)	8 (5.9%)	67 (12.9%)	
Gynecological	62 (9.5%)	19 (14.1%)	43 (8.3%0	
Head and Neck	54 (8.3%)	11 (8.1%)	43 (8.3%)	
Leukemia	102 (15.6%)	25 (18.5%)	77 (14.8%)	
Lung	40 (6.1%)	10 (7.45%)	30 (5.8%)	
Lymphoma	103 (15.7%)	18 (13.3%)	85 (16.4%)	
Myeloma	45 (6.9%)	9 (6.7%)	36 (6.9%)	
Other	52 (8.0%)	14 (10.4%)	38 (7.3%)	

[a] Insomnia item on the Symptom Distress Scale range from 1–5

[b] P-value from Fisher's exact test (t-test for age) for the association between insomnia groups (low vs high) and the given variables at baseline (socio-demographics and clinical factors).

[c] Includes anyone who reported race as anything other than "White/Caucasian" and those who reported more than one race.

Table 3

Characteristics of 120 Participants With Clinic Visit Audio Recordings and Insomnia Item Scores of 4 Or 5[a], Provider Gender and Whether Insomnia Was Discussed

Patient Characteristics Socio-Demographic Factors	Total N=120 (100%)	Discussed (Y/N) No n=42 (35%)	Yes N=78 (65%)	p-value[b]
Gender, male	53 (44.2%)	22 (41.5%)	31 (58.5%)	.25
Age mean(range)	53.5 (24–84)	55.7 (29–84)	52.3 (24–83)	.12
Race, minority or multiple	12 (10.0%)	4 (33.3%)	8 (66.7%)	1.00
Married/partnered[c]	79 (65.8%)	28 (35.4%)	51 (64.6%)	1.00
Low income (<35k HH annual)[c]	35 (29.1%)	13 (37.1%)	22 (62.9%)	.83
Some college/college graduate[c]	82 (68.3%)	29 (35.4%)	53 (64.6%)	1.00
Frequent computer use	89 (74.2%)	26 (29.2%)	63 (70.8%)	.03
Clinical and Environmental Factors				
Service line				.002
Medical	50 (41.7%)	14 (28.0%)	36 (72.0%)	
Radiation	29 (24.2%)	18 (62.1%)	11 (37.9%)	
Transplant	41 (34.2%)	10 (24.4%)	31 (75.6%)	
Study Group				.34
Control	63 (52.5%)	25 (39.7%)	38 (60.3%)	
Intervention	57 (47.5%)	17 (29.8%)	40 (70.2%)	
Cancer Diagnosis				.03
Breast	8 (6.7%)	4 (50.0%)	4 (50.0%)	
Gastrointestinal	9 (7.5%)	3 (33.3%)	6 (66.7%)	
Genitourinary	8 (6.7%)	1 (12.5%)	7 (87.5%)	
Gynecological	18 (15.0%)	5 (27.8%)	13 (72.2%)	
Head and Neck	10 (8.3%)	3 (30.0%)	7 (70.0%)	
Leukemia	20 (16.7%)	2 (10.0%)	18 (90.0%)	
Lung	9 (7.5%)	5 (55.6%)	4 (44.4%)	
Lymphoma	17 (14.2%)	6 (35.5%)	11 (64.7%)	
Myeloma	8 (6.7%)	4 (50.0%)	4 (50.0%)	
Other	14 (10.8%)	9 (69.2%)	4 (30.8%)	
Provider gender, male	28 (23.3%)	12 (42.9%	16 (57.1%)	.35

[a]Insomnia item on the Symptom Distress Scale range from 1–5.

[b]p-value: from Fisher's exact (<5 per cell) or Chi-square (> 5 per cell) for test of association between "Discussed Y/N" and the given variable (Gender, Study Group, Clinical Service, Provider gender); t-test for mean comparison.

[c]Patients with missing values were excluded from the test.

Table 4

Categorization of the Seven Most Common Topics During the Insomnia Discussions Between the 78 Patients With Serious Insomnia and Clinicians.

Topics Discussed	n (%)	Description of the Topic	Examples from the Discussions*
Pharmacological Intervention	39 (50.0%)	Clinicians assessed and or made recommendations about medications related to the patients reported sleeping problems. Patients may or may not have been taking medications for sleep prior to this discussion/visit.	C: "Did you take some sleeping medicine?" P: "Yeah… you prescribed that at the same time as the chemotherapy…" C: "…Sleep, you're taking Ambien." P: "It's not working very well." F: "…I think you slept pretty well last night…" P: "Yeah, because of the Ambien." C: " So with the Ambien, you are sleeping?" C: "Yes" P: "Good. So what time do you go to bed?"
Non- Pharmacological Intervention	10 (12.8%)	There was a discussion of strategies to improve sleep such as reducing liquid intake before sleep, exercise and sleeping patterns.	C: "…limit your naps during the day…nap for an hour or so…try and stay up…"
Concomitant Symptom(s)	36 (46.2%)	Patients often brought up other symptoms or clinicians initiated an assessment of other symptoms while discussing the sleep problems. Common symptoms discussed included pain, anxiety, depression and menopausal symptoms.	P: "I go to asleep for about an hour....and then I wake up, and everything is just soaking…" P: "Oh, no I get up 4 times." C: "Because of …pain?" P: "One maybe for pain, twice to go to the bathroom…"
Change of Subject	15 (19.2%)	Either the patient or clinician may have initiated some discussion regarding sleeping problems but the discussion is changed away from the sleeping problems by the clinician. The clinician also may also appear to bring up the problem again, but changes the subject before patient contributes to the discussion.	C: "Okay, well I'm not going to forget about pain and sleep....talk about that in a little bit....." C: "…despite all that's going on with the sleep and the pain, you think your're thinking clearly, got a good head on your shoulders still?" P: "Yeah, but its harder for me to enjoy things…"
External Factor	10 (12.8%)	Sometimes a factor unrelated to the patient's current illness related problems was discussed as contributing to improved sleep or sleep problems.	C: "What time do you get up?" P: "Uhm, a little bit before 7. Well…but the building that they're doing construction, is really loud."
Sleep improved	9 (11.5%)	Patients reported an improvement in their sleep, and sometimes this was related to an intervention targeting the sleep problem.	C: "And what happened?" P: "Well, you know, ...it helps me fall asleep better…"
Follow-up Recommendation	4 (5.1%)	The clinician recommended either a formal follow-up appointment or informally suggested some re-assessment of the problem or suggested solution.	C: "Are you taking sleeping pill before you o to bed?" P: "Uhm, I take medicine, that's supposed to help people sleep." C: "Let's keep an eye on it over the next few days....we can try a sleeping medicine....."

Abbreviations: C, Clinician; F, Family or Friend with patient; P, Patient.