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ORIGINAL ARTICLE

Trajectory of insomnia symptoms in older adults with lung cancer: using mixed methods

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Abstract

Context A knowledge gap exists in our understanding of the illness and insomnia symptom treatment trajectory in adults with inoperable non-small cell lung cancer (NSCLC).

Objectives Compare valid and reliable sleep-wake measures for insomnia to interpretations of narrative descriptions of sleep to improve our comprehension of sleep-wake disturbances in adults with NSCLC.

Methods This study employed mixed methods (quantitative and qualitative) in a longitudinal design to study adults ($n = 26$) from ambulatory thoracic clinics. Valid and reliable surveys (Pittsburgh Sleep Quality Index, Epworth Sleepiness Scale), 7-day sleep diary, and actigraphy were obtained with interview narrative interpretations of sleep experiences in the context of lung cancer. Data collection occurred at four-time points: baseline (before chemotherapy), pre-second chemotherapy, pre-third chemotherapy, and 6 months from baseline. Sleep measures were compared to interpretations from interview narratives to understand context of survey measures.

Results Objective quantitative results were congruent with interview narrative interpretations that reflected participants' sleep-wake experiences. Objective sleep-wake measures for insomnia over-time described increasing sleep latency and decreasing sleep duration. The interview narratives provided context and insight into participants' subjective insomnia experiences. While participants' insomnia symptoms were present, they were resigned to endure insomnia, and the subjective measures reflected a more positive perception of sleep outcomes.

Conclusion A mixed methods approach provides a deeper understanding of sleep-wake disturbances and the differing quantitative objective and subjective results of sleep measures in the context of the participants' experience of the trajectory of insomnia symptoms before, during, and after lung cancer treatment.

Keywords Insomnia · Mixed methods · Older adults · Lung cancer

Introduction

In the USA, the 5-year survival rate for lung cancer is 16.8%, but is improving and is better than rates reported in western European countries and in Australia [1]. Through newly approved lung cancer screening with low-dose computed tomography in high-risk patients, the detection of cancer at an earlier stage when cure is possible has been achieved in some patients [2]. However, the vast majority of patients with lung cancer are diagnosed with advanced disease and unrelieved symptoms of which some of the most common include pain, fatigue, and insomnia [3, 4].

Insomnia, the most common sleep disorder in America, occurs in one out of five adults and is a risk factor for depression, impaired daytime functioning, and substance abuse resulting in reduced quality of life [5, 6]. Adults with lung cancer are at an increased risk for insomnia because of their older age, compromised respiratory function from lung disease, subsequent treatments for cancer, and the accompanying symptom burden [7–10]. Sleep research in lung cancer is still relatively uninvestigated, but growing [7, 11–17]. Insomnia

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may precede or accompany the diagnosis of lung cancer or result from other symptoms related to the diagnosis or treatments for lung cancer [7, 18, 19]. Among studies involving lung cancer survivors, insomnia was the most prevalent symptom along with pain and fatigue [20–22].

Methodological limitations of previous studies included cross-sectional designs, small sample sizes, single-item measures for sleep-wake disturbances, and limited assessment of sleep quality prior to the initiation of therapy [20–22]. Thus, it is unclear if insomnia predates the lung cancer diagnosis or how sleep changes as a consequence of treatment. Additionally, a considerable degree of incongruence between subjective and objective measures of sleep exists in most [15, 23, 24], but not all [17] previous research. Mixed methods designs support a pragmatic approach allowing for comparing and contrasting quantitative and qualitative data that is different but complementary to address research problems [25].

To understand the incongruence between sleep-wake disturbance measures and the trajectory of symptom experiences, a mixed methods approach [25] was used to quantify the extent of the insomnia symptoms over time and provide insight into common insomnia experiences. Therefore, the purpose of this mixed methods longitudinal study was to compare commonly used valid and reliable subjective and objective sleep-wake measures with interview narrative interpretations of sleep patterns in the context of NSCLC diagnosis and treatment to determine congruence among sleep-wake measures and interview narrative interpretations of sleep. Improving our understanding of insomnia is critical to the development of rational approaches to improve sleep in patients with lung cancer.

Methods

Design overview

A mixed methods design was used in this study based in pragmatism, which combines deductive and inductive approaches, with a problem centered, real world practice-oriented approach [25]. Pragmatism focuses on the primary importance of the research question and pursuit of knowledge and approach needed to answer that question by obtaining different but complimentary data [25]. The longitudinal data described changes in insomnia severity, and interview narratives explored the experiences of sleep-wake disturbances. Both quantitative data and qualitative interview narratives were collected concurrently in a repeated measure format over four times: baseline (7 days before chemotherapy), 7 days prior to second and third chemotherapy, and for 7 days at 6 months from diagnosis. Data collection times were selected to minimize the effects of medications used to reduce side effects of chemotherapy on sleep.

The purposive sample for this study included adults with inoperable NSCLC because of the high levels of insomnia associated with this diagnostic group. Sample size for the quantitative portion of this study was calculated. For a single-sample repeated measures quantitative study, an estimated *average* correlation (from all the correlations among repeated measures) was acceptable [26]. The Pittsburgh Sleep Quality Index Global Score was the key variable used to determine the sample size. The average correlation = 0.50, with a medium effect size = 0.35, $k = 4$, and alpha = 0.05, revealed that 27 participants were needed for 0.80 power [27]. Research team members included experts in quantitative and qualitative methods to compare findings from equally important data sets to merge the data during interpretation by using comparison matrixes (quantitative findings and qualitative themes).

Recruitment

Participants were recruited from the Western New York region, specifically from a Veterans Administration Medical Center ($n = 10$) and a comprehensive cancer center ($n = 16$). Adults scheduled to receive chemotherapy were invited to participate by the participant's nurse practitioner or medical oncologist during the medical oncology consult. Eligibility criteria included a primary diagnosis of inoperable NSCLC, over 21 years of age, and a Karnofsky Performance Status (KPS) $\geq$ 70 (able to care for self, unable to carry on normal activity or to do active work). Exclusion criteria included unable to complete data collection instruments without assistance and medical and/or psychological instability. Participants received incentives ($25) for participating in each phase of the study for a total of $100 if they completed all four-data collection sessions. Informed consent from all individual participants was obtained following institutional review board approval.

Instruments

Demographics A demographic questionnaire assessed personal (age, gender, BMI), lifestyle (smoking history and current use of tobacco, and alcohol), disease (stage and type of NSCLC), comorbidities, and treatment (schedule, type, and dose of chemotherapy) factors.

Pittsburgh Sleep Quality Index (PSQI) Subjective sleep quality and duration within the past month were measured by the PSQI, a 19-item, self-report questionnaire [28]. A global score is calculated, as well as scores for seven subscales: subjective sleep quality, sleep latency, sleep efficiency, sleep duration, sleep disturbances, use of sleeping medications, and daytime dysfunction. PSQI global scores distinguishes good sleepers (≤ 5) from poor sleepers (> 5) and is responsive to changes in

insomnia. Good measures of internal homogeneity, consistency, and validity were obtained through psychometric testing [29, 30].

Epworth Sleepiness Scale (ESS) Subjective daytime sleepiness was assessed with the ESS, an eight-item, self-report questionnaire [31]. The ESS determines "trait" sleepiness based on retrospective reports of dozing behavior in various hypothetical situations leading to an overall level of daytime sleepiness. ESS scores range from 0 to 24, with scores > 10 indicating excessive daytime sleepiness. Internal consistency between the eight-items as measured by Cronbach's alpha (α) is high, ranging from 0.73 to 0.88. [31]

Wrist Actigraphy A wrist actigraph, is a wrist-worn device that continuously records wrist movements. It is, ideally, worn on the non-dominant wrist. The Octagonal Sleep Watch 2.01 (Ambulatory Monitoring, Inc., Ardsley, NY), was the wrist actigraph used in this study. Wrist actigraphy allows simultaneous quantification of wrist movement in three algorithms, but only zero crossing mode (ZCM) is reported in this study. In ZCM, the signal voltage from the accelerometer is compared to the reference voltage, and each zero crossing generates an activity count, thereby recording rhythmic movements. The activity counts are then summarized and stored in 1-min epoch.

Wrist actigraph sleep estimates have been studied in comparison to polysomnography (PSG), the gold standard for sleep studies, where comparisons of sleep-wake cycles from actigraphy to sleep stages from PSG revealed high sensitivity (90%), specificity (95%), and overall accuracy (86%) [32]. Wrist actigraphy sleep variables of interest in this study included sleep duration (amount of time spent asleep), sleep onset latency (min/h to fall asleep), wake after sleep onset (amount of time awake after falling asleep), and sleep efficiency (sleep duration divided by amount of time in bed). These variables were averaged over 7 days.

Sleep diary The consensus sleep diary consists of a log of sleep-wake perceptions recorded by the participant for 7 days while wearing the wrist actigraph [33]. The sleep diary data provided the following subjective variables: sleep efficiency, sleep latency, and wake after sleep onset, sleep duration and daytime naps (duration and length). These variables provided at-home sleep-wake patterns and facilitated accurate interpretation and analysis of wrist actigraphy data. Table 1 describes insomnia symptoms operationalized by variable measurements.

Interview narratives Hermeneutic phenomenology guided the development of the interview questions and interpretive analysis [34]. The interviewer was an expert in qualitative methodology who conducted interviews at a setting convenient to the participants whether home, clinic, or by phone for the subsequent interviews which lasted from 30 to 45 min. Participants were asked open-ended questions to "share stories of their experiences when they first were diagnosed with lung cancer" and "describe their normal sleep patterns before and after the diagnosis including what problems with sleep they were experiencing." Probes were used to expand content to provide rich descriptions of their sleep-wake disturbances such as "tell me more about that," "how did you feel," and "what do you suggest for others in this situation." All interviews were digitally recorded and transcribed word-for-word to provide the textual data for analysis using NVIVO 10.

Quantitative and qualitative and mixed methods data analysis

Descriptive statistics and frequency distributions were generated for participant characteristics and survey data. Paired sample *t* tests were used. The level of significance was adjusted to $p < 0.0125$ for multiple comparisons. All statistical analyses were carried out using SPSS version 20.0.

Action 3.8 analysis software (Ambulatory Monitoring, Inc.) was used to score actigraphy data using ZCM, the primary mode of data collection for sleep estimation. The Action 3.8 sleep scoring algorithm was used to provide summary measures of activity during nocturnal time in bed for all participants.

The interview narratives of the participants' sleep experiences provided the qualitative data, which were analyzed using a modified Heideggerian hermeneutical approach [35–37]. The interpretive team included an expert in hermeneutic phenomenology, a researcher who is an expert clinician and sleep expert, and clinical experts in thoracic oncology. The team approach to data analysis ensured consensus of interpretations supporting researchers' reflexivity to assure the participants' descriptions were rigorously interpreted [36].

The research team analyzed the data in a circular process, identifying related interpretations and practices supported by verbatim excerpts, which were discussed at weekly meetings to reach consensus. Discrepancies in interpretations were clarified by referring to the interview narrative transcripts or verifying with participants at the next interview. Interpretations were identified that were constitutive [37], found in all interviews, and illustrated relationships among narratives, which explicated common practices and shared meanings that formed the basis for understanding the experience over time (four data collection points) as lived by the participants. In hermeneutics, results are always open to new interpretations; however, the hermeneutic process ensured that no unwarranted interpretations emerged and the results were focused and reflective of the text [37].

All data sets were analyzed by mixed methods procedures based on concurrent analysis to answer the research question

Table 1 Insomnia symptoms operationalized by variable measurement

Insomnia symptoms*	Objective measures	Subjective measures
Experience recurrent poor sleep quality or quantity (sleep duration < 7 h)	Wrist actigraphy- - sleep duration	PSQI -Global sleep quality score subscale score - subjective sleep quality Sleep diary - sleep quality
Experience distress or impairment in important areas of functioning	Wrist actigraphy- - Sleep duration - Sleep latency - WASO - Sleep efficiency	ESS -Daytime sleepiness PSQI subscale - Sleep disturbances - Daytime dysfunction
Difficulty in initiating sleep - Sleep latency (< 30 min) - Sleep efficiency (> 85%)	Wrist actigraphy- - Sleep latency - Sleep efficiency	Sleep diary - Sleep latency - Sleep efficiency
Difficulty staying asleep and/or by waking early in the morning and being unable to get back to sleep - Wake after sleep onset (WASO)	Wrist actigraphy - WASO - Sleep duration	Sleep diary - WASO - Sleep duration
Occurs at least three times a week for at least 3 months Occurs despite ample sleep opportunity The problem cannot be attributed to substance use or medication or other sleep disorders	Wrist actigraphy -3 days of sleep latency and sleep efficiency -Increased time in bed -Sleep duration	PSQI subscales - Sleep latency - Sleep efficiency - Sleep duration Sleep diary -Time in bed PSQI subscale - Use of sleeping medications

PSQI, Pittsburgh Sleep Quality Index; *ESS*, Epworth Sleepiness Scale; *WASO*, wake after sleep onset

**DSM-5*, Diagnostic and Statistical Manual of Mental Disorders, 5th ed.)

regarding congruence of sleep-wake measures and interview narrative interpretations. Quantitative data on insomnia [ESS, PSQI, sleep diary, and actigraph scores] were compared to the interview narrative interpretations of sleep-wake disturbances. Data were plotted in matrices over time to demonstrate the complexity of the insomnia symptom trajectory and treatment affects.

Results

Patient characteristics

Among 26 participants, mean age was 66 years, male (62%), Caucasian (84%), married (45%), with at least a high school education (77%) (Table 2). Participants were diagnosed with regional or advanced disease (88.5%) and adenocarcinoma (61.5%) was the most common histologic type of NSCLC. All (100%) of the participants received chemotherapy; the majority (62%) received carboplatin/pacilitaxel.

Attrition was a common issue in this study involving participants with advanced cancer. Out of the 26 participants recruited at time 1 (diagnosis), 21 were still enrolled at time 2 (pre-second chemotherapy treatment), 18 at time 3 (pre-third chemotherapy treatment), and eight completed the study at 6 months from diagnosis (*completers*). Of those who did not complete all four data collection points (*non- completers*), seven participants were deceased, five entered hospice and did not want to continue data collection, and six additionally were lost to follow-up.

Insomnia trajectory from quantitative measures

From the PSQI quantitative data, 93% of the participants had insomnia disturbances at baseline, which included sleeping < 7 h per night (60%), difficulty falling asleep or early insomnia (24%), and 52% had both early and middle insomnia (difficulty staying asleep). Additionally, actigraphy results specified 60% of the participants had sleep efficiency < 85 and 54% had trouble falling asleep (latency > 30 min /night). Waking up after sleep onset (WASO) via actigraphy, occurred in 80% of participants. Outcomes of poor sleep were determined by global PSQI scores > 5 in 85% of the participants and daytime sleepiness scores ESS > 10 in 72.4% of the participants at baseline and 68% at time 2 and 3.

Table 3 displays quantitative longitudinal data on insomnia-related variables. Participants that completed the study (6 months from diagnosis) had a global PSQI of 5.4. Objective wrist actigraphy data revealed a trajectory of increasingly poorer sleep, which included reductions in sleep duration, increased sleep latency, reduced sleep efficiency, and increased WASO during treatment. At 6 months from diagnosis, sleep duration returned to baseline but sleep latency

Table 2 Demographic, disease, and treatment variables ($n = 26$)

Variable	Range in years	Mean (SD)
Age	47–84	66 (9.3)
Comorbidities	n/a	6 (4)
BMI	n/a	28.4 (8.7)
	n	%
Gender		
Male	16	(61.5)
Female	10	(38.5)
Race		
White	22	(84.6)
Black	4	(15.4)
Marital status		
Married	12	(46.2)
Single	1	(3.8)
Separated/divorced	11	(42.3)
Widowed	2	(7.7)
Cancer stage		
II	3	(11.5)
III	11	(42.4)
IV	12	(46.1)
Lung cancer cell type		
Adenocarcinoma	16	(61.5)
Squamous	8	(30.8)
Large cell	2	(7.7)
Chemotherapy		
Yes	26	(100)
Current smokers	9	(35)
Alcohol use	10	(38)

n/a, not applicable; *BMI*, body mass index

and WASO remained high. In contrast, at 6 months, subjective measures from sleep diaries described poor sleep but estimates of increased sleep duration and shorter sleep latency.

Interview narrative interpretations of insomnia and sleep behaviors

During the baseline interview narrative, participants described their usual poor sleep patterns and poor sleep habits that were present and long-lived. Participants had difficulty falling asleep (racing thoughts), staying asleep, and had frequent nocturia (93%) that they related to their frequent awakenings. Table 4 demonstrates the trajectory of insomnia symptoms, frequencies, and verbatim quotes, from the interview narrative interpretations. Insomnia was present initially with narratives of nighttime awakenings and worry. This ability to fall asleep improved with chemotherapy; however, there were more awakenings and trouble falling back to sleep. For the participants that completed the study at 6 months, the insomnia, fragmented sleep, and fatigue continued. Participants described in their interview narratives ongoing poor sleep hygiene that included frequent daytime napping for over an hour (78%), use of caffeine during all hours of the day (88%), use of alcohol (46%), and nighttime use of television (46%). Some participants tried to address their sleep issues by using sleep medication (30%) (data not shown). On the other hand, participants did not perceive their sleep issues as a problem or upsetting. One stated, "I've always had sleep problems."

Comparing quantitative and qualitative results

Interview narrative interpretations described participants' sleep-related symptoms. The first was insomnia-related symptoms of having *trouble falling asleep and worrying minds* that was evidenced by and congruent with increased wrist actigraphy minutes of sleep onset latency (SOL). However, the subjective measure of sleep latency from the sleep diary was reported as less severe. Next, participants described *trouble staying asleep and night time awakenings that fragmented their sleep,* which was evidenced by and congruent with actigraphy measure of increasing wake after sleep onset (WASO). The subjective measure of WASO was less severe than the actigraphy measure. Participants' descriptions of *poor sleep efficiency* included varying bedtime, sleep duration, and wake times, which was evidenced by and congruent with both the sleep diary and actigraphy measures. Overall, insomnia symptoms resulted in shorter sleep durations (< 7 h), which participants described that was evidenced by and congruent with actigraphy measures of short sleep durations. Again, participants perceived longer sleep duration measures in the sleep diary. Table 5 delineates examples of the data comparisons of the mixed methods matrices.

Over time during chemotherapy, the participants did not have as much trouble falling asleep, but they were more tired, the length of daytime naps increased, and they had more frequent awakenings and more difficulty falling back to sleep. Overall, the participants' objective measures were associated with congruent narrative interpretations of poor sleep; however, the quantitative subjective measures reflected more optimism and perceived better sleep that the objective measures and interview narrative interpretations.

Discussion

This study investigated the treatment trajectory of insomnia symptoms in participants with inoperable NSCLC employing a mixed methods approach with a longitudinal design. The sample revealed a 93% prevalence rate of poor global sleep quality with only two reported participants who had better sleep habits and less insomnia compared to the other participants. Participants experienced insomnia symptoms

Table 3 Insomnia symptoms measured over time

Quantitative variable	Baseline mean (SD) $n = 26$	Pre 2nd chemo mean (SD) $n = 20$	Pre 3rd chemo mean (SD) $n = 18$	6 months mean (SD) $n = 8$
PSQI				
Global sleep quality	7.3 (3.8)	6.9 (3.3)	6.3 (3.7)*	5.4 (3.8)
Subjective sleep quality	1.15 (0.68)	0.95 (0.71)	0.94 (0.64)	0.63 (0.52)
Sleep duration (h)	6.6 (1.2)	6.7 (1.1)	6.6 (1.1)	5.9 (1.1)
Daytime dysfunction	1.08 (0.69)	0.95 (0.52)	1.00 (0.69)	1.13 (0.84)
Sleep latency	1.24 (1.27)	1.14 (1.25)	1.05 (1.22)	0.50 (1.07)
Sleep efficiency (%)	85 (13)	83 (11)	82 (16)	85 (13)
Sleep disturbance	1.42 (0.58)	1.32 (0.48)	1.06 (0.42)	1.50 (0.54)
Sleeping medications	0.69 (1.28)	0.80 (1.32)	0.56 (1.04)	0.50 (1.06)
Nocturia item	2.16 (1.21)	2.53 (0.96)	2.33 (1.14)	2.63 (1.06)
ESS				
Daytime sleepiness	7.3 (3.3)	7.19 (3.3)	8.68 (4.6)	6.75 (2.9)
Sleep diary				
Sleep duration (h)	6.4 (2.1)	6.9 (1.8)	6.9 (1.7)	7.1 (1.5)
Sleep efficiency (%)	76 (18)	80 (16)	79 (17)	84 (13)
Sleep latency (min)	41 (47)	42 (62)	23 (18)	27 (21)
WASO (min)	73 (94)	54 (55)	84 (103)	32 (26)
Naps (min)	47 (48)	66 (53)	47 (51)	90 (87)
Actigraphy				
Sleep duration (h)	5.7 (2.6)	6.7 (2.1)	5.0 (2.9)	5.6 (3.2)
Sleep efficiency (%)	74 (19)	81 (17)	74 (19)	74 (21)
Sleep latency (min)	66 (64)	41 (61)	85 (102)	91 (137)
WASO (min)	111 (73)	87 (67)	100 (77)	124 (124)

PSQI, Pittsburgh Sleep Quality Index; *ESS*, Epworth Sleepiness Scale; *WASO*, wake after sleep onset

*Paired *t* tests $p < 0.0125$

(difficulty falling asleep, staying asleep, and/or early morning awakenings) and inadequate sleep durations (< 7 h/night). Across time periods, the participants experienced poor sleep that was part of their daily lives, most slept less than 6 h per night, and had global PSQI scores > 5. Surprisingly, the incongruence between subjective measures and objective measures of sleep indicated that participants were not concerned about the poor sleep they were experiencing, but *expected* it as part of the cancer treatment and insomnia trajectory experience. In addition, when comparing the subjective sleep measures with objective measures, the differences reiterate the subjective perception of sleep differs from actual sleep measures [12, 13, 15]. Actigraphy recorded sleep latency and sleep duration differed from the sleep diary self-report. Participants did not realize their quality of sleep was worse than the non-lung cancer population.

Previous research demonstrated similar reports of poor sleep quality [16, 17], insomnia symptoms [13, 15, 20, 38, 39], and inadequate sleep duration [11, 40]. This study adds to previous research by providing interview narrative interpretations that reflect participants' sleep experiences congruent with objective quantitative results. Although, many participants revealed that sleep was not prioritized in their lives and that participants did not manage, but endured their insomnia. Participants maintained hope for optimal treatment outcomes to give them more time and focused on living their lives. This finding is of concern and suggests that participants lack understanding of the concept and importance of sleep as a fundamental requirement for living their lives to the fullest.

The hope for longer life with treatment that these participants discussed also was the focus of a recent qualitative study in 12 patients with advanced lung cancer [41]. Similarly, hope was linked with various phases of the healing process of restoring meaning, purpose, and wholeness. The role of hope in living life, while not being concerned about sleep, emerged in the current study as a way of masking the severity of the insomnia. Thus, these findings support the value of a mixed methods approach in understanding incongruence of subjective and objective measures and their perceptions of sleep quality.

The majority of participants were poor sleepers at baseline and their sleep often worsened during treatment. Behaviors such as frequent napping may have exacerbated this effect, as two participants revealed that their "days and nights were mixed up." Of note, the timing and practice of increasing fluids to flush out toxic

Table 4 Trajectory of insomnia symptoms from interview narrative interpretations

Time frame	Interpretations	Code-frequencies *n* (%)	Selected verbatim quotes
Baseline	Insomnia-falling asleep	16 (67%)	"I am not sleeping. I have got terrible insomnia now."
Past sleep patterns *n* = 26	Night time awakenings	11 (42%)	"I have been that way most of my life, 4 or 5 h of sleep."
	Worry-racing mind	5(19%)	"I do not have a normal sleep, I doze off for an hour, be up and stay awake for a half hour and then doze off for 2–3 h and this is all in a 24-h period."
	Fatigue	1 (4%)	"I do not sleep at night anyway... I am up all the time during the night. That is just normal for me."
			"When I first found out I had this [Cancer] I could not sleep… but now I try to hide it."
			"Sometimes I want to take a nap but I got to do what I got to do."
Pre-chemo 2	Insomnia-falling asleep	3 (38%)	"I am so tired so I take more naps." "Awaken more often [nocturia] but harder to fall back asleep."
Sleep worsening *n* = 21	Awakening more often	16 (76%)	"I am up during the night going to the bathroom usually a couple of times then I have a hard time getting back to sleep."
	Worry	4 (19%)	
	Fatigue	13 (62%)	"I go to bed with a problem and I mash it over in my head."
			"I would lay in bed at night and had racing thoughts."
			"I am weary but I need to adjust."
Pre-chemo 3	Insomnia	3 (20%)	"Now I get an hour and a half 2 h before I would wake up. Which is not enough really."
Tolerating sleep issues *n* = 15	Sleep fragmentation	8 (53%)	"I sleep the first part of the night about 4 h then I get up and urinate and go back to bed and it gets a little more difficult to get back to sleep."
	Worry	2 (13%)	"I wake up and it is hard to go back to sleep and I have my days and nights mixed up."
	Fatigue	10 (66%)	"I nap all the time."
			"I lay down for a couple of times for an hour or two at a time and sleep."
			"I am sleeping in the afternoon and then I am not tired enough to go to sleep at night."
			"The symptoms keep me awake and they keep me in bed, I am so tired of bed."
			"Chemo is working so It is making me tolerate a little better."
			"I do the best I can and keep on going."
6 months	Insomnia	6 (75%)	"Now I get an hour and a half 2 h before I would wake up. Which is not enough really."
Ongoing sleep issues *n* = 8	Fragmented sleep	6 (75%)	"I sit here watching TV and falling asleep so I go lay down and toss and turn… I think the time of the day was reversed for me."
	Worry	2 (25%)	
	Fatigue	7 (88%)	"The more you fight to try to sleep, the harder it is. You are so busy thinking how to go to sleep that you cannot."
			"My sleep is not real good. Sometimes I can sleep, sometimes I cannot. It depends on how tired I am. I am laying there with my eyes closed does not mean I am sleeping. But I do take naps during the day."
			"I felt anxious, that is how I felt today."
			"I could function. I could do my housework and whatever. It just took longer to do but I could do it. Now it's like, it took me all day to make a bed."
			"Just do not feel good. I do not drink enough, I do not eat enough, I have no appetite, I have no energy, I have nothing. I have total fatigue."

chemotherapy may also contribute to the nighttime awakenings with increased nocturia [42]. Thus, disease- and treatment-related factors may have influenced the worsening of insomnia over time. Since increasing evidence reveals that most patients with NSCLC experienced insomnia, providing effective nonpharmacological interventions at diagnosis may improve sleep quality and quality of life.

Table 5 Mixed methods congruence matrix—examples of data comparisons

Variable	Sleep diary (subjective) mean (SD)	Actigraphy (objective) mean (SD)	Interview narrative verbatim quotes
Sleep latency (minutes) 6 months	23 (18)	85 (102)	"I sit here watching TB + V and falling asleep so I go lay down and toss and turn. The more you fight to try to sleep the harder it is. You are so busy thinking how to go to sleep that you cannot."
			"I cannot go right to sleep I'll get back up. And wander around, or watch TV or do something. Usually, once I do go back to bed, I can go to sleep, but sometimes it does not last very long."
WASO (minutes) Pre chemo 2	73 (94)	111 (73)	"I am up during the night going to the bathroom usually a couple of times then I have a hard time getting back to sleep."
Sleep efficiency (%) Prechemo 3	79 (17)	74 (19)	"I go to bed at nine and I usually get up about five or five thirty, sometimes four. But then by nine o'clock I would take another hour nap, but then I started getting four and a half hours and then I started getting two hours, two and a half hours, last night I just did not get no sleep at all."
Sleep duration (hours) baseline	6.4 (2.1)	5.7 (2.6)	"I have been that way most of my life, 4 or 5 hours of sleep."

In a web-based study of 660 lung cancer patients, the ability to sleep was ranked 4th out of 20-items of importance; the other most important items included overall quality of life, maintaining independence, and able to perform normal activities [43]. Fatigue, the number one reported symptom of cancer, was ranked 5th in that study. In short, sleep is beginning to be recognized by patients with lung cancer as an important quality of life issue. However, insomnia symptoms are often not addressed by clinicians [12, 44]. A component that was not addressed in this paper was circadian rhythm changes related to cancer treatment and survivorship, which is compounded by the practice of daytime napping and fragmented sleep. Future analysis of circadian patterns through analysis of actigraphy would add to the science of sleep, circadian rhythms, and cancer treatment symptom trajectory.

Limitations

Sample size and attrition limit generalizability of study findings to other settings and cancer diagnoses. Major challenges in cancer research are recruitment and attrition, especially in minority, socioeconomically disadvantaged, advanced disease and lower survival rate participants. Commonly cited reasons for participant attrition include transportation/scheduling conflicts and patient/family hardship. Future research must include recruitment strategies tailored to minority and underserved communities who are most at risk for developing lung cancer and the resulting insomnia.

Conclusions

Mixed method is an effective approach to understand congruence of objective and subjective measures and interview narrative interpretations in gaining insight into insomnia symptom trajectory in participants with NSCLC. Interpretations of interview narratives revealed a pattern of poor sleep involving insomnia-related symptoms that were congruent with objective measures yet differed from subjective perceptions. A deeper understanding of the experience of sleep-wake experience provides insight into the incongruence and perspectives of the participants and the role of life priorities in managing or enduring sleep problems.

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Compliance with ethical standards

Conflict of interest The authors have no financial relationship with the organization, the Oncology Nursing Society Foundation, which sponsored the research. The authors have full control of all primary data and agree to allow the journal, *Supportive Care in Cancer*, to review their data upon request.

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