

Experience of insomnia, symptom attribution and treatment preferences in individuals with moderate to severe COPD: a qualitative study

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Abstract: Persons with chronic obstructive pulmonary disease (COPD) are known to have poor sleep quality. Acceptance of and adherence to therapies for sleep problems may depend on how the person with COPD regards the source of his sleep problem, yet little is known about their attribution as to the cause of these sleep symptoms. The objective of this study was to describe the subjective sleep complaints of individuals with COPD along with their attributions as to the cause of these symptoms, and their treatment preferences for insomnia. Three focus groups were conducted (N=18) with participants who have moderate to severe COPD. Focus group data were transcribed, compared and contrasted to identify themes of attribution. Participants reported difficulty falling asleep, staying asleep, and daytime sleepiness. They attributed their sleep problems primarily to their pulmonary symptoms, but also poor air quality (thick humid air) and death anxiety when awake during the night. There was no clear preference for type of treatment to remedy this problem (medication, cognitive therapy), although they indicated that traveling to the clinic was difficult and should be avoided as much as possible. These data suggest that environmental manipulation to improve air quality (eg, air conditioning) and modifications to reduce death anxiety could be beneficial to persons with COPD. In-person multi-session therapy may not be acceptable to persons with moderate to severe COPD, however internet-based therapy might make treatment more accessible.

Keywords: insomnia, sleep, death anxiety, qualitative research, patient preference, attitude to health, COPD

Introduction

Persons with chronic obstructive pulmonary disease (COPD) are known to have poor sleep quality which adversely affects their quality of life.¹⁻³ They have numerous reasons for poor sleep, including pulmonary symptoms (dyspnea, wheezing, coughing), anxiety, depression, and the presence of comorbid sleep disorders such as sleep apnea.⁴⁻⁷ Likewise, poor sleep quality has been shown to worsen COPD severity.⁸ Our recent analysis of 1,142 patients with moderate to severe COPD demonstrated that 55% of patients reported poor subjective sleep quality (Geiger-Brown et al, unpublished data, 2014). Although these data can provide an insight into the prevalence of subjective sleep symptoms in this population, little is known about their explanation as to the cause of these symptoms. It is helpful to understand how individuals experience and explain their problems with sleep, because acceptance of and adherence to different therapies for sleep problems will depend on how the person with COPD regards the source of his sleep problem.

In addition, treatments for insomnia in patients with COPD have been understudied. Several hypnotic medications (zolpidem, eszopiclone, zaleplon, and ramelteon)

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have shown adequate safety for these but are not widely prescribed.^{9–11} Cognitive-behavioral therapy for insomnia (CBT-I) has been shown to be effective for patients with a wide variety of chronic medical illnesses, and has recently been tested in patients with mild to moderate COPD symptoms.¹² But the high burden of traveling to the clinic may make face-to-face treatment less appealing for individuals with moderate to severe disease for whom mobility is quite taxing.¹³

The purpose of this study was to describe the subjective sleep complaints of individuals with moderate to severe COPD along with their attributions as to the cause of these symptoms, and their treatment preferences for insomnia.

Method

Approval for this protocol was obtained from the Institutional Review Board of the University of Maryland School of Medicine. Potential participants were identified from a database of moderate to severe COPD participants who previously participated in COPD Clinical Research Network studies and had given permission to be re-contacted for other COPD studies. The University of Maryland School of Medicine is a collaborator in this research network, and these participants provided questionnaire data about their sleep quality in previous studies. We selected participants with self-reported poor sleep quality (Pittsburgh Sleep Quality Index score >5), living within 30 minutes of the University campus. They were contacted by phone to request their participation in a focus group about sleep problems in COPD participants. Written consent was obtained at the time of the focus group.

Data collection and analysis

Three focus groups were conducted, each lasting 30–45 minutes, using a structured set of three questions with probes to identify sleep problems, causes of those problems, and preferences for treatment of the sleep problems. Participants were compensated for their time (US\$50.00 per session) and parking fees. Saturation was reached by the third focus group in that nothing new was reported or described by the focus group participants.

Each focus group was audiotaped, transcribed, and entered into NVivo 10 to manage data and create an audit trail. The data were categorized according to the three questions, then coded, compared, and contrasted until themes emerged. Rigor was maintained through close consultation between the coders and the focus groups' moderator to assure adherence to the intent of the study and consensus with the findings.

Results

A total of 22 patients were invited to participate. Reasons for declining to participate included poor health (2), difficulty with travel (2), and not interested (1) (more than one reason given by two respondents). The final sample included 18 participants divided over three focus groups from May to October, 2013. Of these, 65% were men, 72% African American and the rest white, with an average age of 57.6 years (range 49–75). Most lived in the urban area surrounding the university; several participants came from nearby suburbs. Only a few were employed, as many had stopped working due to pulmonary symptoms. Two required a wheelchair to travel from the car to the classroom and two others used continuous oxygen. Several were transported from home by family members who waited for them in the lobby. The duration of the focus groups ranged from 30–45 minutes.

All of the participants offered comments, and the separated quotations are from different members of the focus group.

Sleep problems

The majority of participants described difficulty falling asleep, staying asleep, and daytime sleepiness as their major complaints.

I can't sleep at all. It'd be like 3:00 before I go to sleep.

It's like I just said, it's just, you know, I wake up three, four times during the night, you know? You know [...] and it's hard to get back to sleep, you know?

Yeah, I wake up like three or four times at night and it's hard for me to get to sleep – same as she said. And once you get to sleep, it's hard to stay asleep, and then I pay for it the next day 'cause I be sleep [...] drowsy and tired, you know? And I fall asleep on buses.

And so during the day, it's kind of hard to stay awake. If I sit down and get comfortable, I drift off a little bit.

Participants also described their sleep as “restless” and the phrase “toss and turn” was mentioned across all three interviews:

You know, I toss and turn and when I'm sleeping, it bugs me. One participant referred to this phenomenon as “spinning”.

I call it spinning – spinning left, spinning right, spinning this way. You know, rolling over all night long. You just can't get to sleep.

Causes of sleep problems

The majority of sleep problems were caused by indoor “air thickness”, physical symptoms, and thoughts while unable to sleep.

Indoor “air thickness”

Participants in all three focus groups mentioned that a warm, humid room with stagnant air interfered with sleep by making breathing more difficult, and that some participants sleep with air conditioning on “year round”.

But and still, I’d wake up in the middle of the night. I’d be coughing, stuff like that. I had to go to the bathroom and what not, but like I said, really the room temperature and the air thickness and the quality of the air has a lot to do with how I sleep because I’ll wake up if it’s so hot or humid.

You know, I have my set-up with my fan. I gotta have the wind blowing, you know, and the temperature and all of that. I like to be huddled with the covers because that’s a comforting thing, you know?

It’s a combination. I gotta have the right room temperature because if it’s too hot, I’ll cough and wake up sweating and this and that. But if I got the central air on, I can kind of like breathe sort of a little bit because the air is kind of like more thinner, sort of not heavy, you know what I’m saying? It’s not like humid so that helps me out.

Physical symptoms

Participants described having “hard time breathing” when lying down to go to sleep because of “snoring”, “snorting”, “choking”, “chest congestion”, and wheezing which they directly related to their COPD. These three participants underscore well the severity of the problem:

I might wake myself up snoring, snorting, choking. I’m up about ten times a night.

My problem is waking up at all hours of the night, the same way as every other, you know, choking.

[...] about two in the morning I have to get up and uh [...] take a treatment to clear my lungs out, ‘cause I start wheezing and it wakes me up. And after I take my treatment I’m fine and I go back to sleep.

Thoughts when unable to sleep

For many participants, difficulty falling and staying asleep is compounded by upsetting thoughts of death and dying. Some participants also recalled troubling thoughts regarding particularly severe COPD exacerbations, which led to feelings of fear and “panic”. This was a recurrent topic in all three focus groups.

You know, and then I think about us [...] you know, they put you down in the dirt and things [...] thoughts like that, you know, be coming a lot at night. It’s kind of scary.

Just about death sometimes, dying, that you know, scares me sometimes that we’re going to die, you know, even with people killing one another and things, but uh [...] one day we’re going to, you know, (inaudible) of times I’m texting my kids, you know, telling them I love them and stuff like that throughout the night.

I’m willing to try anything because like I said, I’m scared. You know, I’m scared. I panic. When I can’t get that [...] like I can push air out, but I can’t get it coming in and I panic, and it’s like I really can feel the life, you know what I’m saying? And I’m like oh my God, please don’t let me go by myself. Please don’t let me go by myself.

It could be really real because, like I said, I just dread the day that I can’t get to 911, and I can’t tell them where I’m at and, you know, I can’t speak on the phone, you know what I mean? And then I’m panicking because I can’t breathe. It’s a whole thing and then, you know, and it’s suffering. It’s not an easy thing because it [...] for me, it’s suffering because I can’t breathe. You know what I mean? And when you can’t breathe, you can’t do nothing.

I cry sometimes because I think that I ain’t never gonna wake up.

Treatment of sleep problems

Participants discussed a variety of methods for treating their difficulties with sleep, but the major methods were use of medication and equipment, self-management, and staying calm.

Medication and equipment

The role of medication or equipment to treat sleep problems was mentioned frequently. Some participants noted improved sleep with the use of continuous positive airway pressure (CPAP) or oxygen, but they did not agree on the benefits of any particular drug. A few participants shared that they “have to have a pill to sleep”, but others cited difficulty managing prescription sleep aids because the timing of the medication was challenging; not wanting “another drug in my system”; or reluctance on the part of the prescriber, because “he did not want me to get addicted to them”.

Self-management

Participants also discussed self-management strategies that improved their sleep quality. These included positioning, snacking, and being “regulated with my sleep pattern”. Physical activity contributing to good sleep was discussed in all three groups, yet maintaining an active lifestyle was challenging for this group of COPD sufferers:

But I tell you, my sleeping thing, it depends on my activity. I try to be [...] I try to move around as much as I can, you know, but sometimes I'm just too tired. You know, if my COPD is bothering me, I can't go out and do what I want to do or whatever. I have to sit down and just relax and stuff.

Smoking cigarettes was referred to as an attribute of both good and poor sleep. A few participants noted that the quality of their sleep improved when they quit smoking, yet others found that if they woke up in the middle of the night, smoking a cigarette helped, because "it calms me down". Some participants even described using their nebulizer at night "to clear my chest out so I can smoke".

Self-management of sleep emerged as a point of tension for persons with COPD. Physical activity, or even working all day, helped them to sleep better, yet some participants were too encumbered by their respiratory symptoms to engage in exercise, and some reported being on disability related to their COPD. Likewise, cigarettes helped some individuals to relax and fall asleep, but they were aware that smoking worsened their respiratory status.

Staying calm

Waking up short of breath, worrying about death, and recalling fearful situations of breathlessness and helplessness while trying to fall asleep led several participants to develop ways of coping to stay calm and maintain control. Participants cited eating, smoking, using a nebulizer treatment, talking to friends or family, meditating, and breathing exercises as self-management techniques to achieve calmness and control. This led to less fear:

If you stay calm, and like I said go through your little, you know, techniques and things or whatever works for you, you're going to [...] you know, you wind up better [...] but if you stay calm, you know, I think in any situation you'll be all right.

So then once I got to that situation where I knew I can control it, you know, all of my fears just disappeared.

During each of the focus groups, the moderator briefly described cognitive behavior therapy as one way to treat sleep problems. The most salient statement in reference to this treatment was "I do not like coming out no more than I have to".

Discussion

Our qualitative study confirms previous studies showing persons diagnosed with COPD have difficulty sleeping,

and provides new information about the participants' attribution about the cause of their sleep problems. Some patients reported symptoms suggestive of sleep apnea, but regarded these symptoms as directly related to their COPD. It may be that these participants are suffering from overlap syndrome^{6,14} and do not recognize that their symptoms may be related to a sleep disorder. Unlike many other insomnia patients who can point to a specific time or event when they began to have sleep difficulties, and when they began to ruminate about their poor sleep, these participants linked their sleep problems directly to their pulmonary condition. They focused on how their sleep environment and worries about breathlessness and dying make their sleep worse. A pilot study of CBT-I in patients with COPD by Kapella et al¹² recruited a sample of patients with less advanced disease than this focus group sample, and found that in-person multi-session treatment was feasible to them. Improvement was reported using subjective sleep scales, and time awake after sleep onset was reduced. Our data suggest that to improve sleep in persons with more advanced COPD, the typical content of CBT-I would need to be substantially modified to directly address the real concerns about breathing difficulties while alone at night, and justified death anxiety. In addition, in-person multi-session therapy may not be acceptable because of the difficulty of traveling, so alternatives such as internet-based therapy would need to be evaluated.

Modifying the sleep environment by increasing air movement in a cool, low-humidity environment would be as important as eliminating other well-known sleep reducing factors such as extraneous light to improve sleep in these individuals. Death anxiety could be reduced by assisting patients to obtain a life-alert system and by developing a network of social contacts to check on the patients regularly. Cognitive techniques to control fearful thoughts and regain control of their breathing during the night could be a valuable addition to traditional CBT-I content for patients with COPD.

Participants in this study were aware that increased physical activity during the day improved sleep quality. Management of insomnia symptoms is not included in the treatment protocol for most pulmonary rehabilitation programs that improve activity tolerance,¹⁵ yet could be a valuable addition to this treatment as it could reduce the distress of nighttime sleeplessness. The role of hypnotic medication for patients with this disorder remains controversial among physicians despite clinical trials that have demonstrated the safety of certain medications.¹⁶ Not all participants were able to agree on using a hypnotic medication. Some wanted to try medication, but their providers were unwilling to prescribe

it, a finding reported elsewhere in the qualitative literature.¹⁷ Coaching patients with language to help them to discuss their desire to try hypnotic medications may be helpful. Participants in this study reported significant distress at being awake much of the night, with reduced daytime functioning. Helping patients to discuss this with their pulmonologist could lead to better patient control of their own treatment.

Our study is similar to others that also found that persons with COPD who describe feelings of fear, anxiety, and panic related to shortness of breath; two other qualitative studies have found that COPD sufferers fear deeply that they will die of breathlessness,^{18,19} and one other qualitative study found that this fear negatively impacted sleep.¹⁷ The importance of regaining calm and maintaining control in instances of anxiety and breathlessness has been identified elsewhere.¹⁹ One qualitative study of HIV positive women in the People's Republic of China found that the fear of death contributed to poor sleep quality.²⁰ This suggests that cognitive-behavioral therapy targeted to relieving fearful thoughts may be generalizable to patients with other types of chronic illness. Furthermore, the broad cultural sampling in the literature cited above suggests that this therapy may prove effective in a wide variety of populations.

The strength of this study is the rich data provided by a small but diverse sample of participants with varying severities of COPD. Very little prompting was needed to begin or maintain the discussion, and these individuals were quite frank about their own risk behaviors (eg, smoking) and distressing fears. In addition, although the results and discussion are based on only three focus groups, data saturation was reached by the third in that all three focus group participants described similar difficulties and situations.²¹ A limitation of this study, as with all qualitative studies, is that the findings may not be generalizable to all persons with COPD. These study participants were able to travel to the interview site and are not representative of persons suffering with the most severe COPD symptoms who are homebound; however, they still said they preferred to stay at home. Another limitation is that this group was comprised mainly of older individuals with moderate to severe disease. Insomnia symptoms tend to increase later in life regardless of COPD diagnosis,²² therefore, these participants may not be representative of younger people in early stages of COPD.

Conclusion

Individuals with COPD describe difficulty initiating and maintaining sleep, and attribute this to "thick" air, nighttime pulmonary symptoms, and anxiety about nighttime

breathlessness with fear of dying. Their preferences for sleep remedies varied, with some desiring medication and others rejecting this option. Some found that physical activity during the day helped, but this was difficult to achieve. Many thought that leaving home to attend multi-session therapy to improve sleep would be taxing suggesting that alternative methods of providing CBT-I for these individuals, such as online or in-print modules, need to be explored.

Acknowledgment

Funded by the University of Maryland School of Nursing as a Dean's Research Scholar Award to Dr Geiger-Brown.

Disclosure

None of the authors have a conflict of interest that could affect this manuscript.

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