Original Article

# New approach for analyzing self-reporting of insomnia symptoms reveals a high rate of comorbid insomnia across a wide spectrum of chronic diseases

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A R T I C L E   I N F O

A B S T R A C T

Background:  Insomnia is increasingly recognized to be comorbid with one or more medical conditions. This study used an online research platform to characterize insomnia across different mental and physical conditions.
Methods:  A custom cross-sectional survey was fielded online to 31,208 users of the patient community PatientsLikeMe. The survey queried members on National Sleep Foundation-defined insomnia risk (*waking up feeling unrefreshed*, *difficulty falling asleep*, *waking in the middle of the night*, or *waking too early*).
Results:  Complete results were obtained from 5256 patients with 11 comorbid conditions. Seventy-six percent of US-based respondents were at risk for insomnia. Patients who reported *difficulty falling asleep* were found to have nearly twice the odds of self-reporting insomnia (odds ratio [OR]: 1.84; 95% confidence interval [CI]: 1.5–2.1) when compared to those who do not have *difficulty falling asleep,* whereas those who reported *waking during the night* or *waking up unrefreshed* were no more likely (OR: 1.025 and 1.032, respectively) to report that they suffered from insomnia than those who did not experience these issues. Although insomnia was self-reported as severe or very severe across most conditions, few respondents had actually been diagnosed with insomnia by a physician. After adjustment for age and gender, there was an independent and strong effect of primary condition severity on insomnia risk, and those with severe epilepsy (0.93), depressive disorders (0.92), and fibromyalgia (0.92) occupied the highest risk probabilities.
Conclusions:  The high rate of severity and frequency of insomnia across a multitude of mental and physical conditions reveals an opportunity for better disease management through enhanced insomnia awareness.

## 1. Introduction

Chronic insomnia is an under-researched public health crisis affecting 10–20% of the United States (US) general population and costs billions of dollars annually [1,2]. The recent International Classification of Sleep Disorders Version 3 (ICSD-3; 2014) defines insomnia as, "a persistent difficulty with sleep initiation, duration,

consolidation or quality that occurs despite adequate sleep opportunity, and associated daytime impairment." [3] The National Sleep Foundation (NSF) describes five types of insomnia: acute, chronic, comorbid, onset, and maintenance insomnia [4]. However, the diverse nature of the symptoms and causes of insomnia, as well as the wide range of physical and mental disorders that often precipitate insomnia, have made it difficult to develop a consensus on the definition of insomnia, limiting the ability to identify affected populations.

Sleep disturbances, particularly insomnia, are increasingly recognized to be comorbid with one or more medical and neuropsychiatric conditions, including anxiety, depression, diabetes, and Parkinson's disease [2,5–12]. Individuals with insomnia are more likely to have multiple comorbid medical conditions than those without insomnia [5]. In addition, studies indicate that patients with

chronic medical disorders often have fewer hours of sleep and less restorative sleep compared to healthy individuals, and this poor sleep may worsen symptoms of their underlying disorder [6,9,13].

There are several tests which have been used historically to diagnose insomnia, such as sleep logs, blood tests, and sleep studies (ie, polysomnography) [1,14], each with their strengths and limitations. For example, polysomnography laboratories provide a high level of detail, but they are limited by their artificial environment and expense. Traditional paper sleep diaries suffer from "the parking lot effect," that is, patients might make several diary entries at a single time, rather than proximal to the experience [15,16]. These resource-intensive methods also limit the ability of researchers to gain insight into the linkage between insomnia and comorbid conditions on a large scale. The emergence of virtual registries or "patient-powered research networks" offers new opportunities for collecting vast quantities of patient-reported data from patients living with chronic illness reporting from the comfort of their own homes or even their mobile devices [17,18]. Websites that collect patient-reported data about sleep have the potential to inform research about the relationship between insomnia and chronic health conditions in a way that has historically been impossible to do efficiently at a large scale. Furthermore, people with sleep-related conditions are increasingly using the Internet for education, support, and even treatment recommendations [19–30].

PatientsLikeMe (PLM) is a patient-powered research network with patient communities devoted to a variety of conditions, many of them chronic (eg, amyotrophic lateral sclerosis, Parkinson's disease, and epilepsy). In the present study, we used the PLM research network to gather data on the incidence and nature of insomnia in patients already self-defined in the network as having one or more diseases/disorders. We developed and administered a cross-sectional survey to a subset of PLM members in an effort to describe the overall prevalence of insomnia in the PLM population and to characterize the nature of insomnia experienced by PLM members. Our goal was to explore several important questions: (1) What are the rates of insomnia across an online community with major chronic conditions? (2) How do the characteristics of insomnia vary across different mental and physical conditions? (3) What are the contributions of important demographic and disease dimensions to the risk of insomnia?

## 2. Materials and methods

### 2.1. PatientsLikeMe

PLM has more than 300,000 members with over 2000 different conditions. PLM members are regularly invited to share data about a number of symptoms including sleep problems, thus creating a unique opportunity to examine insomnia across many serious chronic conditions. PLM is an adaptable data collection system that collects a range of health data directly from patients, including condition history, specific condition outcomes, symptoms, treatments, side effects, procedures, hospitalizations, blood work, quality of life, and unstructured free text. Upon registration, patients are asked to enter their primary condition – or their chief reason for using the site – and as many secondary conditions as they choose.

Data entry is supported by medical ontologies such as the Medical Dictionary for Regulatory Activities (MedDRA) [31], the International Classification of Functioning, Disability and Health (ICF) [32], the International Classification of Diseases (ICD-10) [33], and by databases such as the US National Library of Medicine's RxNorm (RxNorm) [34]. Patient-submitted terminology is reviewed by trained clinicians and mapped to relevant clinical terminology [35,36]. Users are prompted to submit common personal health data at specific time points (eg, demographics, commonly prescribed treatments, and common symptoms) entering as little or as much information as they like on their chosen schedule.

### 2.2. Custom cross-sectional sleep survey

#### 2.2.1. Survey development

A cross-sectional survey was developed to describe in more detail the overall prevalence of insomnia in the PLM population, to characterize the nature of insomnia experienced by patients, and to understand how patients viewed and addressed their sleep problems. The survey (as with all data entry on the PLM platform) was in English. A pilot survey was tested on 100 PLM users over a period of two weeks in June 2013. Changes were made based on feedback from the pilot group to clarify question wording and streamline branching patterns in the final survey. The final survey consisted of 96 items within nine domains (general health, sleep problems, NSF questions, sleep problem severity, sleep quality, help-seeking, sleep medication use, and effectiveness and attitudes). It included questions on general health, sleep problems, risk of insomnia, treatments used, and impact of sleep problems on quality of life.

Survey responses were then matched by user identification number to available patient profile data, which included demographic information, primary health condition, other comorbid conditions reported, insomnia symptom reports, and typical insomnia severity scores. Insomnia symptom reports are obtained when PLM members are invited to rate five core symptoms that are broadly relevant to chronic conditions: (1) anxious mood, (2) depressed mood, (3) fatigue, (4) insomnia, and (5) pain. Each is a single item and is rated on a severity scale (none, mild, moderate, or severe). A date stamp is recorded at the same time as symptom severity is assessed and patients can add ratings over time. In this way, longitudinal insomnia symptom profiles are collected. Patients who completed at least one insomnia symptom report on the platform were matched to their survey response.

#### 2.2.2. Estimating insomnia risk

The NSF categorizes insomnia by four primary characteristics which include (1) *waking up feeling unrefreshed*, (2) *difficulty falling asleep*, (3) *waking in the middle of the night*, or (4) *waking too early* [4]. These insomnia characteristics can occur independently or jointly. To estimate each respondent's risk of insomnia, participants were asked a series of questions about their sleep problems in the past 12 months. This included the four NSF characteristics of insomnia and the frequency with which patients experience them (*every night/ almost every night, a few nights a week, a few nights a month, rarely*, or *never*). In addition, participants were asked to what extent their sleep problem had an impact on their daily activities (*not at all, a little, some, a lot, extremely*). Those who reported that their problem occurred at least *a few nights a week* and that it affected their daily activities (*a lot* or *extremely*) were classified as being at risk for insomnia, according to the NSF definition [37].

Four distinct sleep subtypes were based on the four NSF characteristics of insomnia described earlier. To possess any sleep subtype, respondents reported any characteristic based on frequency and impact, per the NSF definition. Respondents could identify themselves as having more than one NSF sleep subtype. In addition to the NSF definition of insomnia, survey participants were also asked if they thought they had a sleep problem (*yes, no, not sure*). Those responding *yes* or *not sure* were asked about the extent to which their sleep problems were because of insomnia versus some other condition or reason (including sleep apnea, restless leg syndrome (RLS), depression stress/anxiety, teeth grinding, and worry). Respondents could answer that their sleep problems were due to insomnia by varying degrees of *not at all, a little, some, a lot*, or *extremely*. This measure was further dichotomized before analyses, where those responding *some, a lot*, or *extremely* were those who