Development of Sleep Disorders Scale through Expert Opinion

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Abstract

The purpose of this study was to develop an indigenous Sleep Disorders Scale for identifying the symptoms and prevalence of sleep disorders among Pakistani population. Beginning with an extensive review of the literature, the symptoms of the sleep disorders were identified. Interviews with sleep specialists and sleep disorders' patients were also conducted. An initial pool of items based on the symptoms list obtained from both the sources was generated. Four focus groups were carried out to identify symptoms and general sleep disturbances. Finally, a scale consisting of 81 items was developed. Four experts were then asked to examine the developed scale. Using expert opinion, the items were revised according to their fidelity to the relevant construct and the scale was finalized. A pilot study was conducted and the Cronbach's alpha of the scale was highly reliable ($\alpha = .94$). There is no such scale in use in Pakistan which identifies the symptoms of all main categories of sleep disorders. This scale could be used to screen individuals for sleep disorders and treat them timely.

Keywords: sleep disorders scale, scale development, focus groups, expert opinion

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Introduction

Sleep is a universal human need, and we spend about a third of our lives asleep. Sleep and sleep related disorders have an essential role in relation to health. Sleep is an intricate, multidimensional state of existence and not just an absence of wakefulness. The amount and quality of sleep an individual gets has an impact on the quality of life throughout the daytime. Even though most of the people tend to fall asleep effortlessly and wake up feeling refreshed and revitalized in the morning, many do not (Gradinger, 2011). Lack of sleep, partial or total, acute or chronic, can significantly bring about a change in an individual's behaviour and thinking, and adversely impact the physical, mental, and emotional health (Cappuccio, Cooper, D'Elia, Strazzullo, & Miller, 2011).

Sleep-wake disorders are a group of syndromes characterized by a disturbance in an individual's amount, timing, or quality of sleep, and in behaviours or physiological conditions related with sleep. For the diagnosis of a problem as a sleep disorder, the condition needs to be persistent, cause an individual considerable emotional suffering, and interfere with or hinder his/her occupational and/or social functioning substantially (Chokroverty, 2009). There are different kinds of sleep disorders usually marked by one of these symptoms: problems falling asleep and staying asleep, problems staying awake, problems sticking to a fixed sleep schedule, and unusual behaviors during sleep (American Academy of Sleep Medicine, 2014).

In the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), sleepwake disorders encompass 10 disorders or disorder groups: insomnia disorder, hyper somnolence disorder, narcolepsy, breathing-related sleep disorders, circadian rhythm sleep-wake disorders, nightmare disorder, rapid eye movement (REM) sleep behavior disorder, non–rapid eye movement (NREM) sleep arousal disorders, restless legs syndrome (RLS), and substance/medication-induced sleep disorder. Individuals experiencing any of these disorders usually present with complaints of dissatisfaction regarding the timing, quality, and duration of

sleep. As a result, the patients experience daytime distress and impairment which are seen to be core features of all sleep-wake disorders. (American Psychiatric Association, 2013).

Disorders of the sleep are prevalent and common, and have numerous economic, social, occupational and health consequences. Whether the cause for disturbed sleep is quality, quantity, or timing, it could have several adverse effects on health. Cognitive functioning and mood get affected prominently in addition to fatigue, which is an overall outcome of poor sleep. It is a documented fact now that sleep disorders are a risk factor for developing certain mental conditions as well as medical diseases. Moreover, sleep disturbances can also be a signal for the presence of medical problems like chronic obstructive pulmonary disease, cardiovascular disease, diabetes, Parkinson's and/or Alzheimer's disease (Doghramji, 2004). It is essential to screen out individuals for the presence of any sleep disorders as they can be unaware of any disorders surrounding their sleep at night and inadequate sleep has been observed to have negative impact on health and well-being. Sleep affects immune function, metabolism, cognition, mood and overall quality of life. Usually sleep problems are attributed to problems that occur during everyday life and not to the sleep disorder itself. Though when the sleep disorders are described, their prevalence rates, diagnosis and symptoms are of utmost relevance but of equivalent significance is the fact that how does a sleep disorder manifests itself in the lived experience of the persons having it (Young, 2004). Empirical evidence has shown that sleep loss as well as sleep disorders have a variety of long term detrimental health consequences like a greater risk of depression, obesity, hypertension, stroke, diabetes, and heart attack for the individual. Hence, several years of extensive research has confidently formulated the case that sleep loss and disorders exert a profound influence on an individual's health (Kryger et al., 2002; Stores, 2007). The directly visible consequences of sleep disorders like automobile accidents and errors in judgment are damaging, occur shortly after sleep loss and hence, are easy to be linked to the sleep disorders. However, there are less observable consequences of sleep problems too, like obesity and hypertension, which develop gradually over months and years of inadequate sleep, aren't associated directly to the sleep disorder, but are found to be more prevalent and take a toll on one's health (Colten & Altevogt, 2006). A comprehensive assessment for diagnosis could include detailed patient history, sleep diary record, clinical testing and self-report questionnaires
(Chokroverty, 2009).

The current study aimed to develop an indigenous sleep questionnaire in Urdu for use

with adults (18 and above) for general Pakistani population. The existing scales assess one or a few sleep disorders but no scale is focusing on assessing all the major categories of sleep disorders. Secondly, current scales which assess different disorders are quite lengthy. SDS is concise and developed according to cultural norms of Pakistan. One example could be, that existing scales which assess hypersomnia usually ask if individuals go to sleep while travelling in a public transport or after lunch. However, this is a usual behavior of the public to doze off while in a public transport or after lunch. Hence, it is highly needed to develop an indigenous tool and to validate it on Pakistani population. There is no such scale in use in Pakistan that addresses or attempts to identify the symptoms of all main categories of sleep disorders. Sleep disorders are under recognized in Pakistan and mostly go untreated. The use of this scale both in general and patient care settings could help to identify individuals who could be at risk for a sleep disorder or the ones with high scores on a specific disorder. By identifying individuals with sleep disorders more readily would help to timely treat them and therefore reduce their risk of developing other diseases and improve their day to day functioning.

Literature review

Ample work has been done in the area of sleep disorders in the developed countries including the European region and North America and has focused on its risk factors, treatment and consequences (Leger et al., 2000; Mehra, Stone & Blackwell, 2007). These studies have helped to increase understanding and awareness of sleep problems and their impact on health and well-being both among general people and health care providers. However, the situation is not the same in the developing countries where there is lack of awareness about sleep disorders and a scarcity of health resources too. Sleep disorders are common, however, according to foreign data, sleep disorders often remain undiagnosed, and the situation is likely to be similar in Pakistan.

Research work has not been done in Pakistan to assess the presence of sleep disorders in

the general public or specific samples. Just a few studies have been carried out on student population (Kidwai & Ahmed, 2013; Pasha & Khan, 2003; Surani et al., 2014) and either on sleep quality or insomnia. One survey was conducted on 1488 adults to find out the prevalence of insomnia in urban communities of Karachi, Pakistan and to assess its related factors and the use of sleep medicines. The results were based on self-reported information gathered from the study respondents and revealed 31.3 percent as having insomnia out of which 30.2 percent were found to be using sleep medicines. Individuals who reported psychological distress and health-related issues had higher rates of insomnia than those without distress or health-related problems. These findings are one of the very few in Pakistan and indicate a need for more planned research studies in this area (Kidwai & Ahmed, 2013).

Senthilvel, Auckley, and Dasarathy (2011) conducted a study which emphasized the need for the health care providers to screen patients for the presence of sleep disorders. The use of validated sleep questionnaires for screening was able to identify greater number of patients at risk for the presence of a sleep disorder or its symptoms as compared to the number of diagnoses made by health practitioners. The study was carried out to examine if primary care providers screen their new patients for sleep disorders during their clinic visits, and compare their assessments to the results obtained through validated questionnaires. Adult patients (n = 101) aged 18-65 years completed three validated sleep questionnaires. Excessive sleepiness was found in 28% of the patients and obstructive sleep apnea (OSA) was present in 33%. Probable diagnosis of insomnia was suggested in 30% patients and RLS in 22%. In screening by physicians, insomnia was the most prominent sleep complaint and it was found in 7% sample whereas no patients were diagnosed with symptoms of RLS. This study documented the fact that sleep disorders like insomnia, OSA, and RLS are common but they usually go undiagnosed and untreated because of lack of screening by primary care providers which seems to be a pervasive problem. Validated questionnaires are able to efficiently identify patients who are at risk for sleep disorders in the primary care settings.

Sleep disorders have an impact on the overall well-being or quality of life of an individual. Sleep problems and disorders affect not only the night time sleep but also affect the

daytime activities. A study by Lee, et al. (2009) examined the association between sleep disturbances and health-related quality of life (HRQoL). This cross-sectional study measured sleep disturbances namely difficulty initiating sleep, maintaining sleep, nocturnal awakenings, and daytime tiredness. HRQoL was assessed and information about current medical conditions was recorded too. The results revealed that individuals with sleep disturbances had poor quality of life and as the severity of sleep complaints increased, HRQoL decreased further. Moreover, the adverse association between sleep disturbances and declined quality of life persisted independently even after adjusting for different demographic variables and co-morbidities like diabetes, arthritis, coronary heart disease, and hypertension. Sleep problems themselves have the capacity to impact quality of life and proper management of sleep disorders could have a positive influence on overall well-being of an individual.

Method Objective of the study

The purpose of this study was to develop an indigenous Sleep Disorders Scale (SDS) for identifying the symptoms and prevalence of sleep disorders among adult Pakistani population.

Stages of scale development

The development of SDS went through a series of steps. Items were developed through review of literature, focus groups, and interview with the sleep specialists

Step I: Item generation

Beginning with an extensive review of the literature, International Classification of Sleep Disorders- Third edition (ICSD-3) (2014) and DSM-5 (2013), the symptoms of the various types of sleep disorders and general sleep problems were identified and enlisted. Items from the well-established scales of sleep disorders (Pittsburgh Sleep Quality Index, Sleep Disorders Questionnaire, Bergens Insomnia Scale, the Stanford sleepiness scale, National Sleep Foundation's Sleepiness Test, MOS Sleep Scale, Epworth Sleepiness Scale) were also reviewed and analyzed thoroughly to explore the strengths and limitations of these scales for their administration on indigenous population.

Two practicing sleep specialists were interviewed to get expert advice on symptoms of various sleeps

disorders which they observe in their clinical practice to be included in the scale. The experts gave detailed answers to open-ended questions about the symptomatology of the different disorders and their sub-categories. An initial pool of items based on the symptoms list obtained from the above mentioned sources were generated. Four focus groups were carried out to identify symptoms of sleep disorders and general sleep disturbances from adults. The first two were conducted with 8 men and 8 women respectively without the diagnosis of any sleep disorder age ranging from 21-60 years to identify the general sleep problems. The other two focus groups were carried out from patients of insomnia, hypersomnia, breathing-related sleep disorders, circadian rhythm sleepwake disorders, parasomnias, and restless legs syndrome with the purpose to find out the symptoms experienced by them. The focus groups were conducted to determine if the items generated were considered appropriate by the patients about their experiences with sleep and sleep disorders. Probing questions were asked too for gaining in-depth information about broad categories of sleep disorders. The participants of all the groups were asked to share their experiences of sleep freely and sleep disturbances with specific reference to sleep quality and quantity and additional items were generated. On the basis of interviews, focus groups and literature review, items were generated and a scale consisting of 81 items was developed.

Step II: Item endorsement

Two sleep specialists, one psychiatrist and one psychologist were then asked to examine the developed scale thoroughly. Every item was evaluated for relevance to construct and relevance to clarity. Using expert opinion, the items were revised according to their fidelity to the relevant construct, clarity and redundancy. Items having endorsement between 20-80% from sleep specialists were retained. As a result of the feedback from the experts, eight items were deleted and four items were rephrased.

Step III: Pilot study

A pilot study was conducted on a sample of 100 individuals without any diagnosed sleep disorder

(men=50, women=50) selected through area sampling with age ranging from 18-65 years (M=32.83, SD=12.32). Informed consent was taken and the participants were requested to carefully fill out the scale by choosing one option out of the five responses which they consider most appropriate about their sleep. Items having <20 and >80 endorsements were removed from the scale after carefully reviewing them. Feedback of the sample concerning the scale's items clarity, redundancy, and comprehensibility was incorporated to make the needed changes and a revised version of the scale with 58 items (five point Likert scale) was finalized. The items in the scale were divided into following categories based on DSM-5: Insomnia, Hypersomnia, Sleep-related Breathing Disorders, Circadian Rhythm Sleep Disorders, Parasomnias, and General sleep. The Cronbach's alpha of the scale was highly reliable ($\alpha = .94$).

Convergent Validity of Sleep Disorders Scale (SDS)

The convergent validity of the Sleep Disorders Scale (SDS) was established by correlating the scores on this scale with a highly established measure, Pittsburgh Sleep Quality Index, Urdu translation (Hashmi et al., 2014). Both the scales were administered to 100 individuals (M=45.6, SD=6.37) selected randomly through area sampling. The results showed a significant and positive correlation of .67 ($p<.000$) between the two scales.

Discussion

Sleep Disorders Scale is the first indigenous tool developed for assessing sleep disorders in Pakistani adult population. Unrecognized and undiagnosed sleep disorders have been associated with medical illnesses, impairment in social activities, reduced quality of life, and less productivity at work. After validation, SDS can be used in various settings to screen people for symptoms and presence of various sleep disorders and sleep difficulties which could lead to timely diagnosis, treatment and management of the problem.

There is low awareness among general public, health care professionals as well as policy makers regarding sleep problems and sleep disorders. It not only is a health burden but also pose

a threat to general well-being of the individuals and hence require well-coordinated strategies on the larger scale to improve sleep awareness and control its negative consequences. It requires proper and timely diagnosis and treatment of sleep disorders and for this purpose, need of the hour is to educate and train health professionals for proper surveillance of the general population (Colten & Altevogt, 2006).

Usually the diagnosis of a sleep disorder is done after an overnight polysomnographic study which is a time consuming and costly technique. Self-report questionnaires including SDS are an easy to use way of detecting sleep disturbances in children, adults, elderly, or any specific population. SDS has the potential to detect the symptoms of a sleep disorder and could be an easy and cost-effective method to assess a wide range of sleep parameters in various contexts and provide unique subjective information. Then, if needed, screened individuals could be referred for an objective assessment of sleep for specific diagnosis and intervention.

Conclusion

The purpose of the current study was to develop an indigenous sleep questionnaire for adults. There is no such scale in use in Pakistan that addresses or attempts to identify the symptoms of all main categories of sleep disorders. The validation of SDS is in process and after that it could be used in multiple settings and with various populations to screen individuals who could be having an undiagnosed sleep disorder or the ones at risk for developing a disorder. It will also have the potential to assess individuals with disturbed sleep generally so that timely help be provided to them and their quality of life could be enhanced.

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