Knowledge and awareness of obstructive sleep apnea among patients’ families in Saudi Arabia

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Abstract

**Purpose:** Obstructive sleep apnea is considered one of the most undiagnosed disorders among adults. The reason behind this phenomenon is due to uncertainty of its symptoms. Therefore, this phenomenological-oriented study is designed to explore the knowledge and awareness of patients’ families toward obstructive sleep apnea.

**Methods:** A phenomenological-oriented study was utilized as a qualitative research method. A total of 28 participants who met our inclusion criteria and were selected to participate. They agreed to participate via signed a consent form. A one-on-one semi-structured interview process using the Zoom platform. Transcripts were obtained and analyzed via two independent researchers utilizing an inductive approach.

**Results:** Seven themes emerged from the interviews: lifestyle habits, accompanying symptoms, debilitating conditions, difficulties with CPAP, suffering & fear, coping techniques, knowledge, and awareness among the society.

**Conclusion:** The level of awareness and knowledge among participants was low. The lifestyle of the participants who were exposed to close relatives with OSA is dramatically changed due to many factors such as the patient’s mood, afraid to leave them alone, and fear of losing their loved ones. In addition, participants are afraid of difficulties that may exist if their patients avoid using CPAP or complications of the device itself. Finally, coping techniques were recommended by all the participants to help their loved ones to overcome this disorder.

Introduction

Obstructive Sleep Apnea (OSA) is an upper airway blockage during sleep which may be categorized as partial or full.\(^1\,^2\) The upper airways collapse during sleep due to a decrease in airway muscle tone, primarily during the inspiratory phase of breathing. This results in periodic sessions of hypopnea and or apnea.\(^3\,^4\) These episodes cause a decrease in arterial oxygen saturation which can result in autonomic dysregulation.\(^3\,^4\) Chronic diseases that impact the cardiovascular system, pulmonary system, and neurocognitive system are created over time as a result of these acute changes.\(^1\)

The most common and clinically significant Sleep-Disordered Breathing (SDB) current is OSA which is known to be associated with numerous illnesses such as hypertension, atrial fibrillation, heart failure, cerebrovascular accidents, pulmonary hypertension, and others.\(^2\,^5\) The Apnea-Hypopnea Index (AHI) which is the sum of the number of apneas and hypopneas per hour of sleep is commonly used to measure the presence and severity of OSA. Depending on how hypopneas are defined, OSA prevalence in different countries varies.\(^1\) According to the conservative definition, hypopnea is defined as a 4% decrease in blood oxygen saturation.\(^1\,^6\) According to Peppard Cohort Study, 17.4% of women and 33.9% of men in the US between the ages of 30 and 70 are classified as having mild OSA which is defined as having 5 to 14 events per hour of sleep. The study also reported 5.6% of women and 13.0% of men have
moderate or severe OSA which is defined as having >15 events per hour of sleep. In fact, these numbers will increase annually if there's no proper management for OSA.

The Jackson Heart Sleep Study conducted via Johnson and his colleagues estimated that the prevalence of OSA among African American adults aged 50 to 80 years was 53.6% with moderate to severe OSA affecting 20.4% of the study population. In the Multi-Ethnic Study of Atherosclerosis, moderate to severe OSA was present among 30.3% of white participants, 32.4% of African American participants, 38.2% of Hispanic participants, and 39.4% of people of Chinese heritage. Despite lower obesity rates, Asia has a similar prevalence, presumably because of the craniofacial characteristics of Asians. This study implies that OSA is a condition that affects both rich and developing countries equally. However, only a few Middle Eastern research have calculated the prevalence of sleep apnea.

Prevalence of OSA symptoms among the adult population in Saudi Arabia, the median age of the respondents was 30 years with 26.9% of people having OSA symptoms. Mild, moderate, and severe excessive daytime sleepiness were detected in 12.5%, 8.3%, and 6.1%, respectively, according to the severity of OSA symptoms. In the older group (>30 years; p = 0.004), married participants (p = 0.008), and obese or overweight (BMI 25kg/m², p = 0.002) groups, the prevalence of OSA symptoms was considerably greater. According to BaHammam's study, the incidence of OSA in older persons is relatively higher which is suggested probably due to the physiological and physical changes brought on by aging.

A recent study was conducted via aljawadi in 2021 among 2946 participants, 52.4% were at high risk of OSA with women having a higher risk than men. Obesity was higher among women than men. Almost 56% of the participants reported snoring as a risk factor however, there was no statistical difference between women and men. The factors identified as independent predictors of a high risk of OSA included female gender, living in rural areas, severe cognitive impairments, depression, and anti-depressants usage.

OSA is a potentially life-threatening disorder that is poorly defined and under-reported. Despite increased knowledge of this disease, OSA remains undiagnosed in many patients. A study conducted in the population of Saudi Arabia describing undiagnosed OSA recruited 1925 participants which a mean age of 32.7 years. The majority were men with 57.9%. A large population of 737 participants was found to have a risk of sleep apnea >8 scores on the Epworth Sleepiness Scale (ESS). Of the 737 study participants; 44% felt they had sleep problems with only 5.5% were diagnosed with OSA. Thus, with the lack of awareness and underdiagnosed patients. The aim of this phenomenological study is to explore extensively the knowledge and awareness of patients’ families towards OSA.

Material And Methods

Participants and recruitment strategy
A purposeful and criterion sampling technique was used to recruit participants that met the inclusion criteria: 18 years old and above, and an individual who has a family member suffering from OSA. The pre-screening survey was sent to all sleep centers in Saudi Arabia. Their permission was granted to distribute the survey among their patients. The patients helped us to nominate one of their family members to complete the survey. In addition, a social media platform was utilized to identify an individual who met the inclusion criteria. Upon approval, the participants were asked to attend individual interviews via zoom.

**Ethics, consent, and permissions**

At the time of recruitment, the study objectives were explained clearly and coherently to the participants. The participants' names were not used during the interview to ensure confidentiality. The participants were asked to sign a consent form prior to the interview conduct otherwise, the interview will be postponed. The guidelines in the Declaration of Helsinki were followed to ensure the ethical standards of this study. Participants were informed to have the right to withdraw from the study at any time without prejudice. In addition, the participants were informed that the study is purely for academic purposes and potentially benefits the scholar community.

**Institutional Review Board (IRB)**

The IRB committee of King Saud bin Abdulaziz University for Health Sciences approved this study (SP21J/100/03).

**Data Collection**

Data were collected between August and December 2021 on zoom. At beginning of the interview, the participants were informed that interview will be recorded. In addition, the participants were also informed about the aim of the study, and they can withdraw at any time without prejudice. The method has been used during the interview was semi-structured to help for providing rich data about an individual's experience. The interview for an individual lasted approximately around 30 min. Interviews were carried out by two authors, none of them had prior relationships with the participants. Participants’ names were replaced with pseudonyms in all work products related to the study. At the end of the interview, each participant is gently asked what else he/she would like to add. Two authors [ZN, RH] had regular meetings after each interview to discuss their reflections to demonstrate reflexivity.

The interview guide was structured based on a preliminary consultation with experts in the field of OSA. These questions were constructed carefully to extract the individuals’ experience toward OSA in terms of knowledge, awareness, challenges, coping strategies, and obstacles they faced (Table 1). The Delphi method is utilized to reach 80% agreement for face and content validity for each question.
Table 1
Interview Questions

<table>
<thead>
<tr>
<th>What do you know about sleep-related disorders?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please describe your level of knowledge regarding obstructive sleep apnea and its relationship with snoring?</td>
</tr>
<tr>
<td>What are the challenges that you faced dealing with a family member who has OSA?</td>
</tr>
<tr>
<td>How does that affect your life?</td>
</tr>
<tr>
<td>What are your coping strategies?</td>
</tr>
</tbody>
</table>

Notes:

Abbreviations: OSA, Obstructive sleep apnea; CPAP, Continuous Positive Airway Pressure; AHI, Apnea-Hypopnea Index; SDB, Sleep-Disordered Breathing; Obese Hypoventilation Syndrome (OHS);

Data analysis

The audio recordings were transcribed verbatim. Audio recordings were reviewed extensively by two authors [ZN, RH] to ensure credibility and trustworthiness. The verbatim transcription was obtained in Arabic due to the native language of the participants. Then transcript was translated into English for analysis. Two bilingual translators are hired independently to conduct back translation. Finally, an expert panel committee is established to agree on the final version of the translation.

At the end of the data collection process, the thematic analysis was started to code data utilizing NVivo software. Initially, the authors [ZN, RH] independently reviewed the transcripts to code the data and identified themes. Then, all themes were discussed with all research members to remove the overlap of data in some themes. This process helps the authors to come up with seven themes that are approved by all the research members.¹⁵

The process of validation and reliability were evaluated using the participants’ perception of our preliminary theme analysis. The aim of this validation process is to establish member checking.¹⁶ In addition, the emerging themes were also shared with the external consultant to evaluate the process and findings of this study. This process will help with thematic analysis.¹⁵ Data saturation was met with seven themes emerging: lifestyle habits, accompanying symptoms, debilitating conditions, difficulties with CPAP, suffering & fear, coping techniques, knowledge, and awareness in society.

Results

In this study, twenty females and eight males participated in this study. All of them were suitable based on the inclusion criteria of the study. Seven themes emerged from the interviews: lifestyle habits, accompanying symptoms, debilitating conditions, difficulties with CPAP, suffering & fear, coping techniques, knowledge, and awareness in society. To safeguard the identity of participants, pseudonyms are used throughout the results section's quotations.
Lifestyle habits

The prevalence of obesity is high and increasing, making it a serious threat to public health. Almost all of the interviews conducted pointed towards obesity as a major reason for sleep apnea. It is widely accepted that obesity is one of the most significant contributors to OSA's prevalence and severity.\textsuperscript{17}

‘The doctor explained to me that my mom`s obesity was the main reason that caused OSA.’ (P58)

‘Long time ago, my dad has been overweight, and he has never been in the ideal weight.’ (P87)

Carrying around excess weight is linked to many comorbidities, which are additional health issues. Heart disease, stroke, and diabetes are the three major chronic illnesses linked to being overweight. As stated by an interviewee:

‘My father is overweight, his weight is about 140 or close to 140 kilos, he has diabetes, hypertension, and heart problems as well.’ (P87)

Maintaining a healthy weight can be difficult when you don't have the energy you need because of sleep apnea. People who are overweight often have trouble breathing and have chest pain even when they don't exercise very much. Being deprived of normal, rejuvenating sleep due to sleep apnea has serious consequences for daily life. A person's risk for sleep apnea increases in direct correlation with their body mass index (BMI). Most people who suffer from sleep-disordered breathing snore. When a person is overweight, they are far more likely to snore.

‘At the beginning of his sleep, he woke up as someone was choking him, he woke up and took deep breaths (describing the sound of his breath), it’s like he gasped a lot.’ (P106)

Sleep apnea is made more likely by vices like alcohol and tobacco use. A person's upper airway might become blocked if they drink alcohol because the muscles in their mouth and throat relax. When the muscles and tissues of the upper airway are impacted by alcohol or nicotine, snoring can occur. Many persons who snore sleep on their backs because this position causes their airways to be compressed. Sleep apnea is strongly linked to tobacco use.\textsuperscript{18} Inflammation of the upper airway caused by smoking (through inhalation of smoke) can restrict the airway's capacity for unrestricted breathing, making it more difficult to quit smoking. Nicotine is a stimulant that has been shown to disrupt regular sleep cycles and lead to the less deep sleep that occurs more frequently. Smokers who give up the habit greatly reduce their chances of developing sleep apnea. Inflammation of the upper airway, brought on by smoking, might make it difficult to take deep breaths. As stated by a respondent:

Snoring happens because of obesity or habits because my uncle smokes. It is the person's habits that can cause the problem.

(P118)
Accompanying Symptoms

Even if a person with sleep apnea may not realize they have the condition, a bed partner or observer may notice problems. Overnight apnea syndrome causes airway constriction. When a person has more than a predetermined number of obstructive apneas in an hour of sleep, they are diagnosed with obstructive sleep apnea (OSA). When being asked by the respondents, majority of them said that the patients felt these symptoms who have sleep apnea such as an interrupted sleep, wakes up tired, heavy snoring, wakes up suddenly during night, felt lazy and lethargic the whole day with fatigue, drowsiness, headache, sleeps while sitting, difficulty concentrating, and shortness of breathing.

She snores loudly not always just if she is tired. However, her snoring is not like a normal person's. (P115)

'We currently don't let him drive because even while he is driving, he may sleep. I mean he may be sitting with us, and we have guests or sitting together without guests, suddenly he sleeps, suddenly we wake him up because his sleep position is not good.' (P87)

My grandmother needed to stay in the hospital for about two weeks because she was dizzy and lost consciousness. Because of shortness of breath, flu, mucus, and phlegm, her airway was blocked. (P66)

Debilitating conditions

Inadequate sleep has been linked to weight increase, creating a vicious cycle. Pharyngeal fat is a type of neck fat that develops in overweight people. Since this is the case, snoring is among the most prominent signs of sleep apnea. Other than this, the respondents also mentioned a few other conditions associated with sleep apnea patients they are currently dealing with such as tonsils, asthma, adenoids in the nose, special needs, Prader-Willi syndrome, Rheumatoid, and Parkinson's disease.

... I took him to the hospital, and they said he had thyroid. (P86)

She has Prader-Willi syndrome. She is extremely obese and retardation, and she has been learning disabilities. She suffered from cramps previously and her feeding was through a gastric tube. After three years, they expected that she had sleep apnea because she was always exhausted while she was sleeping, and she woke up in a bad temper. (P111)

Difficulties With CPAP

Continuous positive airway pressure (CPAP) is a vital treatment for OSA, it can be challenging to get used to at first. While interviewing, many respondents believed that CPAP is really challenging. They found it
unsuitable in terms of size or design and the marks that it makes on the face. Hence the patients were having difficulty getting acclimated to the CPAP mask. After-effects like sneezing and a stuffy nose made it difficult to breathe, making the process of using it a nuisance in and of itself. This was causing worry and making the patients hard to go to sleep. Complaints of shortness of breath are another common CPAP side effect, however, this is typically experienced as a sensation rather than an actual physical limitation. Since a properly operating CPAP machine does not limit the amount of air that may be inhaled, the only symptom experienced is a lack of air.

The doctor gave her CPAP device, but unfortunately, it was annoying to her, and she did not use it until this time.

(P58)

Especially when he wakes up and sees signs of the marks on his forehead and around his eyes, that’s why he sometimes doesn’t use it at night before his work.

(P76)

A few respondents stated that the family’s condition was worse prior to the use of the device; however, the sufferings of the entire family have improved as a result of the use of the CPAP device. The patient is improving and resting soundly after using it.

He always uses the device while sleeping to avoid apnea and we are sticking to it. Therefore, he wears the mask of the device then he sleeps….there is a huge change in his condition before and after visiting the doctor and using the device.

(P16)

Suffering & Fear

During interviews, respondents highlighted that if a family member is diagnosed with sleep apnea, not only does he/she suffer from it, but so does the entire family. Sleep apnea can strain the heart, increase blood pressure, and affect one’s disposition. Due to a lack of adequate deep sleep, the patient may have difficulty thinking rationally. And nighttime snoring or gasping for air will disturb the family members. Depression caused by untreated sleep apnea can make it difficult for a person to maintain healthy family relationships. Sleep apnea is frequently related with decreased workplace productivity and increased accident risk on the road.

One of the changes was we banned him from driving, and we brought a driver for him. Moreover, we tried to make a healthy diet for him. Someone must be with him to take care of him and make sure that he takes his medication on time.

(P16)

Worry and exhaustion, he is always worried and thinks a lot.
Look, since she encounters difficulties during sleep at night. During the day her morals become a little bad. She becomes a little angry, so I feel this thing has affected our lives.

Coping Techniques

The most effective treatment for sleep apnea, continuous positive airway pressure (CPAP), has been linked to weight increase in certain research. Overeating, obesity, and a slowdown in fat loss during calorie restriction are all more common in people with OSA. High blood pressure and heart failure have been linked to OSA, which is linked to obese hypoventilation syndrome (OHS). The risk for OHS increases with body mass index; people with a BMI of 50 or more are nearly twice as likely to get the condition. By decreasing abdominal fat, weight loss boosts lung volume and enhances airway traction, reducing the likelihood of airway collapse when sleeping. When questioned about the most effective treatment for sleep apnea, CPAP has the support of a large percentage of respondents.

The problem is the snoring, we are both suffering from it, and sometimes the sound reaches out the living room. So, I started to adapt to it and I have to be beside him to wake him up if he is suffocated.

I understood that when he used the device and woke up the next day, he told you metaphorically that life was different. I felt happy.

My father must lose a lot of weight in order to begin the treatment plan, after which we can try to find other ways to solve the issue.

'The device has changed a lot in her life.'

Knowledge and Awareness in Society

Sleep apnea is an issue that can cause severe health complications. A significant number of individuals worldwide suffer from sleep disorders, and their incidence may be growing. Sadly, many of these illnesses may go undiagnosed and neglected in therapeutic settings. Although physicians recognize that enough sleep is vital for patient health, the issue is frequently overlooked in general practice. Efforts are being made to raise awareness of sleep disorders, but more must be done to improve the situation, especially in poorer nations. The globalization of Western culture, which includes technology, sleeping,
and activity patterns, as well as eating, suggests that sleep problems may continue to develop in other nations. Only through continued lobbying, research, and education will significant progress be made. In addition, it is crucial that clinicians employ their knowledge and current research surrounding sleep disorders in order to identify these issues in the clinic and treat patients accordingly.

Maybe as with raising awareness about hypertension, diabetes, and kidneys, we should dedicate a day for sleep apnea, like volunteering and raising awareness in malls and among people.

(P67)

Educating the community on World Health Day about the clinics in public places, such as the market and parks.

(P66)

Making events in public places will help, conferences or training courses as an introduction to these matters. These things may can educate the community a little.

(P103)

**Discussion**

To our knowledge, this is among the first studies to employ qualitative methods to describe the level of awareness and knowledge of patients’ families on OSA. We found that there was low awareness and poor knowledge of OSA among the patients’ families. The study demonstrated that the number of respondents that were able to properly state at least one risk factor, symptom, health consequence, and treatment option for OSA which were relatively low. This finding demonstrates the inadequate level of knowledge around OSA. The respondents’ range of replies were also constrained with the two most typical and obvious response in each category making up the majority of the responses such as obesity, snoring aggressively, sleeping at inappropriate times, and many more as stated in the results. None of the respondents mentioned other associated symptoms such as nocturia, morning headaches, and depression. In addition, the respondents also did not acknowledge that OSA was linked to metabolic and cardiovascular conditions like diabetes mellitus. Though, the respondents linked obesity with significant other comorbidities.

In a population-based study carried out in Canada, Walker et al. (2010) conducted interviews with 1174 participants to determine the level of OSA awareness by phone surveys. The study populations were risk patients and not their relatives and family members. It was reported that more than 60% of respondents were able to describe OSA symptoms including snoring and choking during sleep with 56% of respondents being aware of the disorder. These respondents, however, were only permitted to participate in the study if they had sleep apnoea risk factors with 58% mentioning a history of snoring. The results suggest that even though the study population was not typical of the overall population the level of awareness and knowledge was low.
According to this study’s findings, conventional media sources were the most popular information source. This shows that conventional media channels are still significant even if more individuals are obtaining their information online. Therefore, in order to connect with their intended audience such as public health campaigns such as dedicated days and activities, conferences, and seminars. These public health campaigns will need to use a variety of media channels. The respondents heard about OSA via friends and family either through word of mouth from a friend or family member who had been diagnosed with the OSA.\textsuperscript{1} Thus, improving rates of sleep apnea diagnosis is suggested that it is important for raising OSA awareness.\textsuperscript{21}

The respondents of the study reported initial experience of using CPAP was challenging. Most of the study participants found it to be challenging with difficulties associated with adjustment and comfort of the mask. Despite the challenges, participants acknowledged having positive responses to CPAP treatment for their family members such as reporting improved sleep, reduced snoring, and increased energy. The findings of our study align with other studies in the literature which described the positive initial experience and response to CPAP treatment as effective for the patient.\textsuperscript{22,23}

**Limitations**

This study is considered a phenomenologically oriented study that in fact findings of this study cannot be assumed to be generalizable. However, this type of study strives to create an in-depth structure of the individual's lived experience. In addition, the majority of participants were female who either complain about snoring or cared about their loved one. In addition, all the participants had similar ethnicity. Thus, future studies need to include large participants from diverse backgrounds. This study was also limited to interpretation instead of quantitative analysis. This means that the research was open to interpretation and analysis via the researchers. This opens a platform to assess the data and construct of interpretation of the data. Other variables such as financial difficulties, family conflicts, and other family members with ongoing medical conditions that may contribute to the knowledge and awareness of OSA and its ongoing management and requirements from the patient’s relatives.

**Conclusion**

The respondents demonstrated a low degree of knowledge of all aspects of OSA. Their lack of knowledge sources demonstrates the necessity for medical personnel to increase their OSA awareness and understanding. Despite good results regarding OSA symptoms, the general community demonstrated a lack of understanding of its implications. To educate practitioners and the public about the disease, ingenious educational programs must be established. Continuous positive airway pressure therapy is the current treatment of choice for people with moderate to severe OSA. As a method of treatment, lifestyle adjustments such as quitting smoking, losing weight, and increasing physical exercise have been identified.
Declarations

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Disclosure

The author reports no conflicts of interest in this work.

Data Availability

The datasets used and/or analyzed during the current study available from the corresponding author on reasonable request.

References