

SCIENTIFIC INVESTIGATIONS

Facilitators and barriers to getting obstructive sleep apnea diagnosed: perspectives from patients and their partners

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Study Objectives: Obstructive sleep apnea (OSA) is a prevalent and debilitating condition that is significantly underdiagnosed. The majority of adults sleep with someone—a partner. Partners can play a significant role in the patient’s OSA diagnosis. The goal of this work is to describe facilitators and barriers to OSA diagnosis as discussed by patients with OSA and their partners.

Methods: This was a qualitative secondary analysis with results drawn from 20 dyadic interviews, conducted 1 couple at a time, in 20 newly diagnosed adult patients with OSA and their partners. Qualitative interview data were analyzed using conventional content analysis.

Results: Facilitators of OSA diagnosis were partners pushing patients to seek care, patients actively seeking care, and care providers identifying the patient’s risk of OSA. Barriers to OSA diagnosis were patients’ lack of serious attention to symptoms, patients’ negative perceptual framing of diagnosis and treatment of OSA, and poor coordination of health care services.

Conclusions: We recommend engaging partners in the OSA diagnosis and developing educational and behavioral interventions to raise public awareness about OSA. It is important to educate clinicians on atypical presentations of OSA. Further investigation is needed to evaluate the impact of health care services on OSA diagnosis.

Keywords: obstructive sleep apnea, couple, diagnosis, qualitative content analysis

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BRIEF SUMMARY

Current Knowledge/Study Rationale: To address the significant underdiagnosis of obstructive sleep apnea (OSA), there is an urgent need to understand why and how individuals seek medical evaluation for OSA. The majority of adults sleep with a partner, and partners can play a significant role in the patient’s care-seeking for OSA and diagnosis process.

Study Impact: This is the first study to describe facilitators and barriers to getting OSA diagnosed from the dyadic perspective of patients and their partners. Findings of this work add to our understanding of major facilitators and barriers to the OSA care-seeking and diagnostic process, which makes a meaningful contribution to the literature in addressing the serious issue of underdiagnosis and delayed diagnosis of OSA.

INTRODUCTION

Obstructive sleep apnea (OSA) is a growing sleep-related breathing disorder affecting approximately 1 billion people worldwide.¹ Despite its high prevalence, only about 1 in 50 individuals with symptoms suggestive of OSA is evaluated and treated.² Undiagnosed and untreated OSA can lead to excessive daytime sleepiness,³ disturbed mood,⁴ impaired cognition,⁵ diminished quality of life,⁶ and increased mortality.⁷ OSA also independently increases the risk for hypertension,⁸ cardiovascular diseases,⁹ diabetes,¹⁰ and stroke.^{11,12} OSA’s high prevalence and negative health consequences have led it to be viewed as a serious public health threat.¹³ As a result, Healthy People 2030, the national objectives to improve health and well-being over the next decade, has proposed to “increase the proportion of adults with symptoms of OSA who seek medical evaluation.”¹⁴ In order to achieve this goal, there is an urgent need to understand why and how individuals seek medical evaluation for OSA.

According to the 2005 Sleep in America Poll,¹⁵ nearly two-thirds of adults sleep with a partner, and one-quarter to one-third

of cohabitating couples report that their relationships are negatively affected by their own or their partner’s sleep problems or excessive sleepiness. The impact of OSA extends beyond the individual patient.^{16,17} Partners frequently report disturbed sleep because of patients’ snoring and gasping, or from their concerns with patients’ breathing abnormalities.¹⁸ Partners can play a significant role in the patient’s OSA diagnosis and treatment.^{19–22} The goal of this study was to understand the experiences of getting OSA diagnosed from the patients’ and their partners’ perspectives, with a focus on determining facilitators and barriers to their care-seeking and diagnosis process.

METHODS

Overview

This is a qualitative secondary analysis of existing qualitative data, which reflect recommended guidelines and best practices for conducting qualitative secondary analysis.^{23,24} The parent study is a National Institutes of Health–funded research project

examining spousal involvement in continuous positive airway pressure (CPAP) treatment (R15NR013274; principal investigator: L. Ye).^{20,21,25} The original data collection was focused on learning about the couples' experiences of managing CPAP treatment together, with the main findings published identifying major facilitators and barriers to CPAP use.²⁰ Secondary analysis of qualitative data is a common and cost-effective approach to maximizing the usefulness of existing data. In the parent study, participants included newly diagnosed patients with OSA and their partners and the couples were interviewed after the first 3 months of CPAP treatment. The experience of the patient's OSA diagnosis was mentioned by all couples in the interviews but was not sufficiently focused on in the primary analysis. The purpose of the current analysis was to describe facilitators and barriers to OSA diagnosis. Interview dialogue between the patient and the partner about the OSA diagnosis was selected and coded from the original transcripts. The same qualitative research expert (D.G.W.) from the parent study guided this secondary analysis. In addition to the principal investigator and the qualitative research expert from the parent study, a new qualitative research trained team member (W.L.) selected information-rich data from the original transcripts and devised the coding process. This new member offered fresh perspectives uninfluenced by the primary analysis. Both the parent study and this secondary analysis received approval from the Institutional Review Board.

Participants

The parent study conducted face-to-face semi-structured in-depth open-ended interviews with 20 couples, including adult patients with newly diagnosed OSA and their partners. The interviews were conducted 1 couple at a time, after the patients completed the initial 3 months of CPAP treatment. The participants' characteristics were reported in detail previously.²⁰ Briefly, there were 16 heterosexual couples (including 11 male patients with female partners and 5 female patients with male partners) and 4 same-sex couples (including 3 male patients with male partners and 1 female patient with a female partner). The majority of the couples were White (75%) and non-Hispanic (90%). The average age for both partners was approximately 50 years, and participants had been together for an average of 16 years (ranging from 2 to 49 years). For the patient participants, 30% of them were diagnosed with severe OSA and 45% were considered less adherent to CPAP treatment, with an average use of fewer than 4 hours per night.

Data analysis

In consultation with the qualitative research expert (coauthor D.G.W.), the research assistant (W.L.) and the principal investigator (L.Y.) served as the primary data analysts. Conventional content analysis was used to identify topical codes, generate clusters of codes, and develop categories.²⁶ The codes for facilitators and barriers were generated from the data rather than from preselected codes. QRS International's NVivo 12 qualitative data analysis software (QRS International Americas Inc.) was used to facilitate data analysis and data management. Codes were assigned to segments of the interview data, which

were reviewed and refined. Through an iterative process, codes were grouped together into categories based on similarities. Categories were generated using a 2-person consensus approach (W.L. and L.Y.). As categories and their constitutive codes were refined, they were validated in team meetings with the qualitative research expert. Analysis involved checking the fit or referential adequacy of data with codes (eg, checking preliminary findings against raw data). Validity and credibility were further ensured by debriefings on coding approaches and internal audits of coding by research team members.

RESULTS

Facilitators of OSA diagnosis

Based on the qualitative data provided by both patients and their partners, 3 categories of facilitators of OSA diagnosis were identified. These facilitators are as follows: (1) partners pushing patients to seek care, (2) patients actively seeking care, and (3) care providers identifying the patient's risk of OSA. Each facilitator category is illustrated with representative direct quotes from the participants.

Partners pushing patients to seek care

Partners were identified as the most important factor for patients to start the care-seeking process leading to OSA diagnosis. When describing their experiences of OSA diagnosis and treatment, patients often expressed appreciation for their partners, highlighting the importance of engaging partners in the entire process. For example, 1 patient stated, "I think from the very beginning the spouse should be involved. We are just lucky that we can have family together in some of my [primary care] consultation." Another patient suggested, "It would be helpful for the partners to know more about [the disease]. Maybe have information available at your doctor's office so you can bring it home to talk to your partner about it."

Partners also cared about the health of the patient and made the patient aware of OSA symptoms. For example, 1 partner said, "I remember many many years ago I used to say to him, 'you are not breathing' ... maybe I will wake up one morning and he will be dead." Another partner observed and informed the patient, "[You] have trouble, take a nap, [and] fade out at the end of the day." Partners also complained that their sleep was disrupted by the patients' loud snoring, sometimes leading to the couple sleeping separately. One partner requested of the patient, "Can you please do something about this because you are not the one suffering, I am." Additionally, partners pushed the patient to seek care. The biggest "struggle" perceived by both patients and partners was initiating the conversation about the sleep problems with their health care provider. The following conversation illustrated a typical scenario where the patient was under pressure from the partner to seek care. Eventually, the patient did seek care, out of concern for the partner.

Partner: I don't know what took you so long to do it. I was trying to figure out all those years why he hasn't [been] talking to his doctor about this. And he would come back from his appointment and I'd ask, "Did you talk to your doctor about it?" and he'd say "Oh no."

Interviewer: So, what was it that got you ... ?

Patient: ... Like I said, working on a lot of stuff and trying to improve our relationship and I thought that would be a good thing to do.

Patients actively seeking care

Patients were motivated to seek professional care due to various symptoms and alerting events. Bothered by various OSA symptoms in their daily lives, including interrupted sleep, feeling tired during the day, frequent napping, and nodding off while driving, they were prompted to seek care. One patient stated, “I have depression. I take several medications, and just as a risk factor ... obviously sleep can really integrate into being a problem.” In addition, alerting events triggered patients to seek professional care. One patient recounted, “I used to wake up and feel disoriented, like I couldn’t concentrate ... I wasn’t breathing right ... I think I was going down to where people say I could have had a heart attack or a stroke.” Examples of alerting events included experiencing a medical emergency such as having a panic attack, hearing about someone’s sudden death during sleep, and observing drastic improvements in health after OSA was diagnosed and treated. Other people in the couples’ social network were important in sharing this type of information with them. One patient recounted, “I was talking to a guy who runs the gym [who had suffered from undiagnosed OSA for 15–20 years probably] ... and his life has changed now that he is on the CPAP machine.”

Care providers identifying the patient’s risk of OSA

Having open discussions with care providers and being offered health education facilitated diagnosis, making a difference in participants’ understanding of the OSA diagnosis and associated risks. As 1 patient reflected, “It’s all about education ... the sleep study [is] not a big deal, but if you don’t know anything about it” This patient described how he received education from the provider relating to the sleep study, which addressed his initial resistance against pursuing the diagnosis. A patient with high blood pressure who did not think he stopped breathing during his sleep but instead snored loudly, stated that “the PCP [primary care provider] is aware of if you have the sleep apnea it can affect your other conditions. So, he was the one that referred me to a sleep study.” This referral led to his subsequent diagnosis and treatment. Some participants described that their care providers identified the risks of OSA while working to address other health issues such as hypertension and fatigue, thereby leading to the OSA diagnosis. For example, 1 patient reflected, “It was my neurologist who was working to try and get my blood pressure under control and nothing was working ... it was his idea actually to go and do a sleep study ... where it’s really hard to control blood pressure in the past he has seen it can be attributable to sleep apnea.”

Barriers to OSA diagnosis

Participants’ descriptions were classified into 3 categories of barriers to receiving the OSA diagnosis. These barriers were (1) patients’ lack of serious attention to symptoms, (2) patients’ negative perceptual framing of diagnosis and treatment of

OSA, and (3) poor coordination of health care services. Each barrier category is illustrated with representative quotes from the participants.

Patients’ lack of serious attention to symptoms

Patients described being accustomed to living with their symptoms as if the symptoms were normal, thereby delaying diagnosis for a long time. Some patients failed to make the connection between their symptoms and a sleep disorder. As 1 patient commented, “I probably went about 23 years where I felt like I was waking up feeling hung over and not having had a drop of alcohol ... [I] got used to a new norm of fatigue.” In addition, some patients did not prioritize taking care of their symptoms. They described being preoccupied by other challenges in their lives, such as a busy work schedule and caretaking of family members. For example, 1 patient mentioned delaying his care-seeking because “my older son has his own [health] issues ... as if we didn’t need enough stress.”

Patients’ negative perceptual framing of diagnosis and treatment

Patients’ negative perceptual framing of OSA, diagnosis, and treatment was a barrier to timely care-seeking. The perception of stigma related to OSA impeded having open conversations with care providers. As 1 partner commented, “Everyone over the age of 45 pretty much has a CPAP machine. And I think if [the patient] realized it is so common, it might have also taken the stigma away from having the conversation.” Patients also described preconceived negative notions of the diagnostic procedure and treatment of OSA, such as thinking it is “too overwhelming to go to the doctor.” Perceptions of the inconvenience of the sleep study, anticipated high cost, and the cumbersome nature of CPAP treatment were also described. One patient recounted, “I have heard horror stories that [CPAP] is an extreme cost ... like insurance doesn’t cover it ... then there is the sleep study. So, I think a lot of potential patients put all these barriers in their head.” Patients also expressed their concerns around the sleep study. This was a major reason to avoid seeking care. One patient described the sleep study to involve a “wrapping like a lie detector” and another imagined himself “with all those wires and the [lack of] privacy.” Avoiding seeking care and denial delayed getting an OSA diagnosis, as remembered by 1 patient: “I was in denial about it ... I didn’t want to go through that process of sleep study ... the preparation is more of a problem to me, but once I got the machine and used it, I should have done it a long time ago.”

Poor coordination of health care services

Participants described lack of coordination and fragmented care throughout the health system as influential factors in delaying diagnosis and treatment. Dissatisfaction with health care services resulted in tension for both patients and their partners. For example, participants described the coordination of services as disjointed spanning from the original assessment and sleep study and continuing to the insurance coverage. Furthermore, participants described the long time the entire process took. One participant commented, “The doctor had another organization do

the home sleep study test. That took a month or 2. Then it was another 2 months to get the results back with the doctor. And, then, another month or 2 to get with the insurance company. It just like took forever.” This was perceived as sometimes leading to a significant delay of diagnosis and treatment, even if the patients were actively seeking help. Another patient stated, “I have actually done a sleep study 10 years ago ... and the doctor then said that I should have been on this machine back 10 years ago.” Participants also complained about a lack of education, poor communication, and sometimes inconsistent messages from their care team regarding the OSA diagnosis and management options. One couple aptly expressed the discontent experienced with the diagnostic process, stating, “even though we try to go into [the CPAP treatment] with open minds, that was not a good start.”

DISCUSSION

The present study is the first to describe the facilitators and barriers to getting OSA diagnosed from the dyadic perspective of patients and their partners in their own words. Findings of this work add to our understanding of major facilitators and barriers to the OSA care-seeking and diagnostic process, which makes a meaningful contribution to the literature in addressing the serious issue of underdiagnosis and delayed diagnosis of OSA.

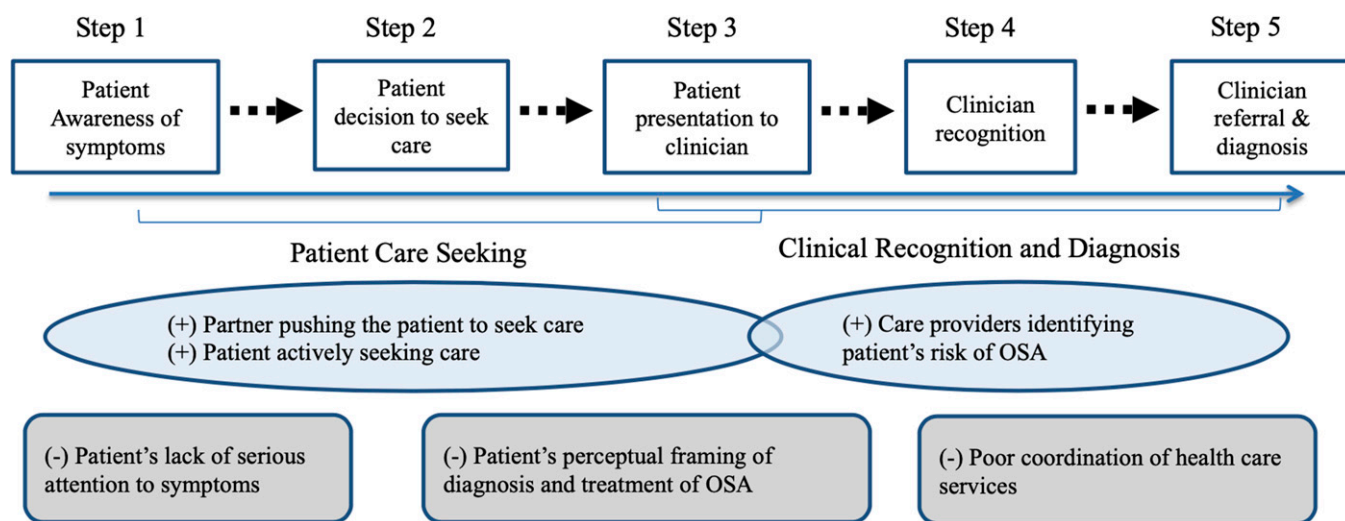
One strength of our work was to describe the experience of OSA diagnosis from a dyadic perspective. Due to the dyadic nature of sleep and the collateral damage of OSA to partners, it is important to understand both patient and partner perspectives regarding the experience of OSA diagnosis. In a previous qualitative study describing the experiences of couples managing OSA and CPAP treatment, the format of focus groups was used, with patients and partners interviewed separately.¹⁸ Without capturing the relational dynamics between the couple, this

format may have limited the understanding of the experience of the dyad. Our study using a dyadic interview with 1 couple at a time allowed the couple to guide the dialogue and describe their experience within the context of their relationship dynamics. In addition, this dyadic interview stimulated responses that may not have been remembered without the presence of the other partner and provided more control for the couples to construct their experiences.²⁷

A delay in diagnosis was frequently mentioned by the couples, especially by the partners when they described their frustration in pushing the patient to seek care. The lag time between the initial appearance of OSA-related symptoms and a positive diagnosis can vary significantly, with the average duration reported to be approximately 10 years.²⁸ It remains largely unknown how this delay in OSA diagnosis may have a significant impact on health. In a study applying cluster analysis to identify distinct OSA clinical phenotypes, 3 clinical subtypes based on OSA symptoms were revealed: a disturbed sleep group, including members with the highest probability of experiencing insomnia-related symptoms; a minimally symptomatic group, who were relatively asymptomatic and more likely to feel rested upon waking up; and a sleepy group, who presented with classic OSA symptoms including excessive daytime sleepiness and witnessed nighttime breathing pauses.²⁹ The probabilities of having comorbid hypertension, diabetes, and cardiovascular diseases were found to be highest in the minimally symptomatic group. It was suggested that the potentially longer lag time prior to the OSA diagnosis in these patients who were minimally symptomatic might have contributed to the observed higher probability of developing comorbidities in this group.²⁹

As suggested in **Figure 1**, to be diagnosed successfully, an individual has to follow steps that include the following: (1) awareness of OSA symptoms, (2) a decision to seek care, (3) a presentation of symptoms to clinician, (4) clinician recognition

Figure 1—Facilitators and barriers to OSA diagnosis.



OSA = obstructive sleep apnea.

of OSA presentation, and (5) referral for OSA diagnostic evaluation. The major facilitator and barriers identified in our dyadic interviews make significant impacts on all of the steps in the OSA diagnostic pathway. Symptoms typically trigger patients' health-seeking behaviors, and a referral for diagnostic testing for OSA depends on successful recognition of symptoms by both patients and clinicians. However, patients' care-seeking behavior can be complicated, with full recognition of symptoms not necessarily leading to the decision or action of seeking care. The majority of the scientific investigation of OSA diagnosis focuses on how to facilitate clinician recognition of OSA and how to diagnose OSA accurately, which is at the end of the OSA diagnostic pathway and cannot adequately address the issue of underdiagnosis of this debilitating disease. The earlier steps in this pathway, which are particularly related to patient care-seeking behavior, have not gained much attention but will help answer the key question of why the majority of individuals with OSA have not been evaluated and treated.

Based on our findings of major facilitators and barriers to OSA diagnosis, we make the following 4 key recommendations for clinical practice and future investigations. First and foremost, it is essential to include and engage partners for the OSA diagnosis. The partner can be the single most important factor for the patient to initiate care-seeking and get OSA diagnosed. At the same time, we have learned that both the patient and partner are willing to be involved, including being engaged in the conversation with the care providers and in learning about OSA and its treatment. For individuals living with partners, the partners should be included in the clinical inquiry for OSA diagnosis and should be considered as a part of any successful strategies aiming to facilitate care-seeking and clinical recognition of OSA.

Second, education and behavioral interventions are clearly needed to raise public awareness of common OSA symptoms and the negative health consequences caused by OSA. This can help address barriers to OSA diagnosis, such as patients' lack of serious attention to symptoms and their perceptual framing of diagnosis and treatment. Mobile health can be an ideal strategy to achieve this goal by engaging users and reaching hard-to-reach individuals with a high risk of OSA. Many minorities and low-income individuals use smartphones as their only method of Internet access.³⁰ Given the pervasiveness, low cost, and convenience of mobile technology, mobile health interventions hold great potential to facilitate care-seeking. For example, mHealth interventions can use brief storytelling or narrative videos to feature alerting events commonly seen to trigger or motivate patient care-seeking for OSA (eg, experiencing or hearing about a medical emergency that is relevant to sleep, observing drastic health improvements in others after OSA diagnosis and treatment), which is a strategy demonstrating success for behavioral change.^{31,32}

Third, to achieve successful and effective clinical recognition and diagnosis, it is important to educate care providers for atypical clinical presentations of OSA. Data from both clinical and population-based cohorts around the world have confirmed that distinct clinical phenotypes of OSA exist,³³ with approximately half of the patients who may not present classic OSA symptoms such as excessive daytime sleepiness.²⁹ This clinical

heterogeneity in symptom presentations and associated comorbid conditions poses challenges to OSA diagnosis. Screening OSA in high-risk populations, such as patients with hypertension, may significantly increase occurrences of OSA diagnosis.³⁴

Finally, poor coordination of health care services needs to be further investigated and understood as influential in the delay of OSA diagnosis and treatment. Approaches at the organizational level and systems level focused on care coordination among different care providers and various stakeholders are required to remove this barrier to OSA diagnosis. Constrained by a limited number of specialized providers, health systems are challenged in taking care of a large number of individuals with OSA. Innovations, including simplified home-based diagnostic and care models and the incorporation of non-sleep-specialist-directed care, are promising in the management of uncomplicated OSA.³⁵ The impact of these innovations on facilitating OSA diagnosis deserves further investigation.

This study may be limited by its nature of being a qualitative secondary analysis. In the parent study, the couples were chosen to share their experiences with CPAP treatment based on their CPAP adherence and the diverse demographic and clinical characteristics. The participants' descriptions were grounded in their own experiences and memories. The participants were free to talk about their experiences related to OSA diagnosis, but we did not specifically probe questions related to the diagnosis in the interviews. Nevertheless, this is a good start to understand the perceived facilitators and barriers to OSA diagnosis from the couples' experiences and perspectives. Future investigation of the original data collection should consider including patients with various lag times between the initial appearance of OSA-related symptoms and a positive diagnosis and including patients with distinct clinical phenotypes of OSA.

In this study we aimed to describe facilitators and barriers to OSA diagnosis from a wide range of perspectives, including both male and female patients and their partners (opposite and same-sex), and did not explore the impact of the couple's sex makeup on the experiences of getting OSA diagnosed. An earlier study of married couples in a Hispanic community reported that men tended to underestimate their own snoring while women tended to overestimate their male partners' snoring.³⁶ This discordance may support the hypothesis that compared with female patients, male patients are more likely to be pushed by their female partners to seek care leading to OSA diagnosis. The couple's relationship dynamics and coping style may further influence the role that partners play in the OSA diagnosis process. Sex differences in OSA clinical presentations may also influence patients' symptom awareness, care-seeking, and clinical recognition of OSA.^{37,38} In addition to sex, growing bodies of evidence support the existence of racial disparities in the prevalence, risk factors, clinical presentation, diagnosis, and treatment of OSA.³⁹ For example, a meta-analysis reported a higher prevalence of and more severe OSA in African American patients compared with White patients.⁴⁰ How sociocultural factors such as sex, a couple's relationship, and race influence OSA diagnosis need to be further investigated.

In conclusion, data from dyadic interviews have identified major facilitators and barriers to OSA diagnosis based on

experiences from patients with OSA and their partners. These major facilitators and barriers can significantly influence the OSA diagnostic pathway, including the steps of patient care-seeking, effective clinical recognition, and diagnosis of OSA. Findings from this study suggest great opportunities for clinical practice and future investigations. We recommend engaging partners for OSA diagnosis and developing educational and behavioral interventions to raise public awareness about OSA. It is important to educate care providers on atypical clinical presentations of OSA and to increase OSA screening in high-risk populations. Further investigation is needed to evaluate the impact of health care services on OSA diagnosis. Continued research is warranted to understand factors influencing patient care-seeking behavior and clinical diagnosis of OSA, which will ultimately address the alarming underdiagnosis and delayed diagnosis of this prevalent and debilitating condition.

ABBREVIATIONS

CPAP, continuous positive airway pressure
OSA, obstructive sleep apnea

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