

Assessment of an Educational Booklet for Patients to Facilitate CPAP Adherence

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Abstract

Background: The standard clinical treatment for obstructive sleep apnea (OSA) is continuous positive airway pressure (CPAP). Studies have shown that patient education concerning OSA and its treatment increase adherence to treatment. With the objective of contributing to patient education and to facilitate adherence to CPAP treatment, a highly illustrated booklet "Sleep Apnea, CPAP and Me" (48 pages) was created to help educate patients about OSA diagnosis, and treatments.

This study aims to evaluate this educational tool for OSA and thus increase adherence to CPAP treatment.

Methods: A sample of 80 participants diagnosed with sleep apnea was asked to read the booklet "Sleep Apnea, CPAP and Me" and complete a survey comprising 21 questions. The survey was administered in three sleep clinics in Ontario. Statistical analysis was performed using a one-sample paired t-test.

Results: The mean age of participants was 58 years (± 15), 56% male, and most (64%) had been using their CPAP machine for > 1 year. Majority of participants (88%) responded that when starting their CPAP therapy, the content presented in the booklet would have provide answers to most of their pre-treatment concerns. Furthermore, they described the content in the booklet as either "definitely" or "mostly" comprehensive and easy to understand. In a planned second edition of the booklet, participants requested several additions: more statistics, pictures, graphs, and "anecdotes".

The mean difference in subjective daytime sleepiness before and after CPAP treatment was -2.4 (95% CI: -3.1, -1.7; df=52; $p < 0.001$) for subjective daytime sleepiness and 1.9 (95% CI: 1.2, 2.6; df=52; $p < 0.001$) for daytime alertness.

Conclusion: Patient feedback from the survey has shed light on required improvements for the planned second version of this booklet, which will have the title "Sleep apnea: Who gets it? Why does it matter? How to diagnose and treat it?". This article highlights the need for more tailored patient-centric approaches to increasing patients' knowledge about obstructive sleep apnea and its treatments.

Keywords: Sleep Apnea; Continuous Positive Airway Pressure; CPAP; CPAP Adherence; Patient Education; Sleep Apnea Treatment

Introduction

The development of patient health literacy has effectively enhanced therapeutic adherence in several diseases, including type II diabetes mellitus and antidepressant therapy [1]. Furthermore, it effectively improved health outcomes in a meta-analysis of 153 studies that evaluated patient education and adherence [2-4].

Obstructive sleep apnea syndrome (OSA) is a highly prevalent form of sleep disordered breathing, with a recent review estimating a prevalence ranging from 9% to 38% in the general population, with a prevalence as high as 90% in group samples of elderly men [5]. OSA is a common chronic condition associated with morbidity and adverse health outcomes such as neurocognitive impairment, hypertension, cardiovascular and cerebrovascular disease [6]. Importantly, untreated sleep apnea has been shown to predict hypertension, stroke, depression and mortality. This emphasizes the importance of optimizing treatment adherence [7]. There are multiple treatment options for OSA, however, the current clinical standard remains the application of continuous positive airway pressure (CPAP) throughout the night [8]. While surgical interventions, oral appliances, positional devices, and weight loss regimens represent possible treatments, CPAP is typically recommended as the first line of treatment due to its low risk, robust efficacy and relative ease of use [8].

Approximately a decade ago, a study of CPAP adherence was conducted in two clinics, one in an underserved area and the other in a large metropolitan area. The study showed (using a high criterion to determine adherence to CPAP treatment of six nights per week, six hours per night) an unusually high CPAP adherence of 84% and 77%, respectively. In a subsequent review, a range of factors facilitating adherence to OSA treatment were demonstrated [8]. One of the discrepancies between the two clinics was that in the rural clinic, there was a rotating CPAP vendor on-site at the time of the follow-up appointment when patients received the diagnosis of OSA. If prescribed CPAP treatment, the patient could acquire the device immediately following the visit. When a similar arrangement was created for the urban clinic, it showed a clear increase in CPAP adherence as well. Research evidence has demonstrated that the shorter the duration is from receiving a CPAP prescription to acquiring the device is predictive of better adherence. Furthermore, it could be argued that the greater expectation of CPAP adherence to be a minimum of 36 hours per week, as compared to the standard recommendation at the time, of four days per week, four hours per night (i.e., 16 hours per week) might have tipped the balance, sending a “message” that the expectation is that CPAP would be used all the time. In contrast, the more traditional approach (which was arbitrarily decided in the early days of CPAP usage and widely used) had patients believing that even a short duration of use would be helpful and sufficient. A significant barrier to CPAP treatment of OSA remains optimizing treatment adherence, defined as the degree to which the patient follows treatment recommendations [9]. Prescribing CPAP is of little benefit to patients if they cannot, or will not, follow treatment recommendations. The exact frequency and duration of CPAP use required for a therapeutic have not been quantified, resulting in an inconsistent definition of CPAP adherence in the existing literature [8]. Under Medicare rules (U.S.), patients must use the CPAP for four hours a night for at least 70 percent of the nights in any 30-day period within three months of getting the device [10]. Generally, adherence is considered regular use of the CPAP machine, and its recommended use is 6-8 hours per night. CPAP adherence data has consistently illustrated a trend of low adherence across a wide range of populations [11]. Despite noted efforts within the field, such as behavioural intervention, clinically significant improvements in CPAP adherence have been difficult to replicate [12].

In a randomized controlled parallel-group study by Falcone et al. (2014) [13], patients were presented with and had their polysomnography SpO₂, and flow curves explained. It was noted that these patients were more likely to attend their follow-up appointments and had better CPAP adherence at 12 months than their counterparts in the parallel group. This suggests that patient awareness and knowledge strongly influence adherence to CPAP therapy.

It was clear from a review of CPAP adherence [8], that for many patients, education about the benefits of high usage of CPAP is a significant contributor to increasing adherence to CPAP use. One of the review authors (with three colleagues) went on to produce a booklet for patients entitled “Sleep Apnea, CPAP and Me”. Research has shown that a patient’s early experiences with CPAP can predict subsequent therapy adherence [14]. As a result, the first version of “Sleep Apnea, CPAP, and Me” was published as an upstream

intervention method inclusive of relevant and clear educational material to ensure improved experiences with CPAP in the early stages of treatment. The booklet was written for the general public and included many pictures and graphics that describe OSA, its consequences, diagnosis, as well as the details and importance of CPAP therapy[15]. Providing each patient who was subsequently diagnosed with sleep apnea and prescribed CPAP treatment with a copy of the booklet led to further increase in adherence to CPAP treatment in both the rural and the metropolitan clinics by 7% (i.e., achieving an adherence rate of 91% and 84%, respectively). Following the depletion of resources to distribute the booklet, some reduction was noticed in adherence to CPAP use in both clinics.

As a result of observing a recent decline in treatment adherence it was decided to produce a more up-to-date version of the initially provided booklet.

Before creating the new version, it was decided to survey patients who had been diagnosed with sleep apnoea and were attending the clinic for a follow-up appointment. Patients were asked to complete a systematic questionnaire about the content of the booklet and were specifically asked for comments and criticisms. The intent was to be able to improve on the initial booklet.

Comments and criticisms from the patient's review of the original booklet have been addressed in the new booklet. In light of the patient's recommendation in the survey, additional sections on 'diagnosis of OSA'; 'paediatric sleep apnea' and more information on oral appliances have been added. The new version is titled "Sleep apnea., Who gets it? Why does it matter? How to diagnose and treat it?" (72 pages) with a plethora of pictures and graphics that reflect the broader scope of the subject.

The present study investigates patient's perspectives and feedback on the first edition of this booklet, titled "Sleep Apnea, CPAP & Me" [15]. As noted above, this was to gather information for a revised and broader version of the booklet with predominantly new authors that will take a broader perspective as informed by this study.

Methods

The participant sample (n=80) includes a sample of patients chronically treated for OSA from three Ontario sleep clinics: Parry Sound (n=50), Toronto (n=20), and Mississauga (n=10). Participants were provided with and requested to read "Sleep Apnea, CPAP and Me". After reading the booklet, a survey was distributed to participants. This was designed to evaluate participant perspectives of the booklet. Participants were additionally asked to rate their daytime sleepiness level on a ten-point scale (0-least sleepy, 10-most sleepy) and daytime alertness (0-least alert, 10-most alert) before starting CPAP treatment and while completing the survey to assess for specific educational gaps of CPAP users based on objective identifiers.

One-sample paired t-test was used to assess the change in these variables.

Results

The study's population (N=80) had a mean age of 58 years (± 15), 56% male, most of which (64%) had been using their CPAP machine for more than one year. The majority (59%) reported using their CPAP machine for at least 6 hours per night. The vast majority (88%) answered that the first edition of "Sleep Apnea, CPAP, and Me" would have answered the questions they had when initially beginning CPAP therapy, 83% indicated the content in the booklet was either "definitely" or "mostly" comprehensive and easy to understand. Two-thirds of participants answered that the booklet was either "moderately" (29%) or "very" (38%) useful. Participants were also asked what they would like the new version to contain. Common answers were statistics (15%); pictures (14%); graphs (14%) and anecdotes (10%).

The most common source of confusion was a specific graph comparing the survival rates in chronic cigarettes smokers, severe OSA, and moderate OSA.

Most participants (71%) reported that receiving the booklet when first diagnosed with OSA would be the most useful, rather than receiving it when purchasing a CPAP machine (8%), or after using their machine for one month (3%). Roughly half (53%) of participants reported not recalling receiving information regarding alternative treatments to CPAP in OSA.

The mean difference in subjective daytime sleepiness before starting CPAP treatment and while completing the survey, (on a ten-point scale) was -2.4 (95% CI: -3.1, -1.7; $df=52$; $p<0.001$), while the mean difference in subjective daytime alertness rating was 1.9 (95% CI: 1.2, 2.6; $df=52$; $p<0.001$), indicating a reduction in daytime sleepiness and increase in daytime alertness after commencing CPAP therapy.

Most helpful pages:

Pg. 7: “Why does it matter if I have sleep apnea” with diagram of associated medical problems

Pg. 5: What is sleep apnea? History and physiological description with diagram

Pg. 33: Overlap of sleep apnea and depression with Venn diagram

Most impactful pages:

Pg. 7: “Why does it matter if I have sleep apnea” with diagram of associated medical problems

Pg. 8: Medical problems associated with sleep apnea with diagram of car accident risk

Pg. 33: Sleep apnea and depression with Venn diagram

Which page would you eliminate?

Pg. 9: Financial implications of OSA (no pictures)

Pg. 10: “Who is susceptible to sleep apnea?” with pictures of an overweight man, lady with a narrow airway and enlarged tonsils

Discussion

This survey aimed to evaluate, analyze, and improve the contents of the original booklet to improve patient education during the early stages of OSA diagnosis and CPAP use. Our study’s sample was comprised of participants with relatively high adherence to CPAP therapy (more than five hours per night). It can be argued that the participants who completed the survey are not representative of the entire population of patients treated with CPAP, as our participants were more adherent to maintaining contact with the clinic and attending follow-up visits. In our view, the advantage of this population is that it can provide unique insights related to their lived experiences with OSA and CPAP treatment.

A significant number of patients indicated information in the current booklet would have helped answer many of their questions and concerns when first diagnosed with sleep apnea. Receiving a diagnosis of OSA can be challenging to comprehend as CPAP therapy can seem to pose a significant inconvenience and negatively impact nightly routine. Patients frequently describe initially feeling uncomfortable sleeping with the CPAP device, which can subsequently lead to distress and sometimes anxiety. In addition, patients also feel overwhelmed following diagnosis. This may limit them from voicing queries or concerns regarding their treatment. The educational booklet about OSA and CPAP, “Sleep apnea, CPAP, and Me,” aims to alleviate some of these concerns and assist patients and their families in taking active and informed participation in their treatment. However, it became apparent that the spectrum of topics covered in the booklet was somewhat limited. In the last decade the field of OSA therapies has expanded and we concluded that additional details about alternative treatment options should be included in the next version of the booklet to broaden patient knowledge and to facilitate informed decision making (especially on oral appliance treatments, on how OSA is diagnosed, and sleep apnea in children and adolescents).

Furthermore, the booklet's effectiveness in answering patient questions can be summarized by the following comment from a patient "I thought this book was great. It gave me more information than the "unsure" internet. This booklet should be in every family physician's waiting room."

Another strength of the booklet is its analog nature, which allows for convenient access to scientifically accurate information. Our society's current technologically oriented trend has led patients to search the internet for answers to frequently asked questions; however, it can often be difficult for patients to distinguish fact from misinformation pertaining to OSA and CPAP. In addition, patients may be disinterested in the process of critically analyzing the credibility of the voluminous information online. This provides a substantial opportunity for clinicians to intervene and ensure patients are not only receiving accurate information, but information that is comprehensible and will translate to improved quality of life.

Health communication research has suggested that it is possible to increase reader attention, comprehension, recall and adherence to instructions through the use of images and pictures in written material [16,17]. Results from the survey drove our team to include additional informative and understandable graphics, in the new version of the booklet.

To gather patient opinions and perspectives to improve the content (both text and visuals), participants were asked to provide feedback on complex or confusing concepts. Several participants expressed difficulty comprehending a graph in the original booklet, and as a result, the caption of this graph has been improved to provide a more explicit depiction of the data.

Contrastingly, participants were further asked to provide feedback on helpful or impactful content to allow authors the opportunity to assess why certain content resonated with participants. Content on "Why does it matter if I have sleep apnea?" and the interplay between sleep apnea and depression were voted as the most helpful and most impactful content respectively.

The generalizability of our findings is limited by the specificity of our data, which relates to the original booklet exclusively. Furthermore, the data was collected at one time point using a single survey. Asking participants to retrospectively rate subjective sleepiness and alertness which may be unavoidably rated in comparison to the participant's current state. Moreover, not everyone completed all the items on the surveys. Most questions have a small proportion of missing data due to some participants failing to fill out the corresponding section of the survey. Research in identifying and reducing barriers to long-term CPAP adherence remains a priority. In addition to the new version of the booklet becoming available, a comprehensive new book, "CPAP Adherence. Factors and Perspectives" (37 chapters) [18], will be available (contemporaneously with the latest version of the patient booklet) for sleep medicine clinicians and other professionals in healthcare. Several parameters pertinent to CPAP adherence have been evaluated, including the severity of the disease, age, sex, race, socioeconomic status, education, sleepiness, and personality styles [19]. Several CPAP device-related features have further been assessed, including aspects such as heated humidification, mask type, pressure, and cost. Given that such parameters may not have the ability to be modified, the purpose of evaluating these factors is to develop interventions in the form of education, supportive care, and behavioural modifications that may result in long-term CPAP adherence [19].

The cost of printing and distributing the educational booklet to patients is less than 1% of the cost per patient of the process of diagnosing and treating OSA (i.e., conducting a physician visit followed by a sleep study, a follow-up physician visit, and purchasing a CPAP device). It is reasonable to assume that in a cohort of patients with lower treatment adherence, providing newly diagnosed patients with such a booklet might increase adherence rates much more dramatically than in our patient sample (which was already demonstrating high adherence to CPAP therapy).

Conclusion

Patient education continues to serve as an important vehicle for increasing adherence to treatment recommendations, patient care, and quality of life. The present study gathered patient feedback on a booklet discussing OSA and CPAP treatment. Results from a population with high adherence rates suggested that the booklet was useful, mostly understandable and would have answered initial questions following diagnosis. Furthermore, critical feedback was considered, and acted upon for the updated version of the booklet, which include more graphics and clarify certain figures to ensure improved patient comprehension and education.

The new booklet is available from sleeponthebay.ca to the readers of this article.

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