

Brief Communication

A preliminary study of psychological factors affecting patients' acceptance of CPAP therapy for sleep apnoea syndrome

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Abstract

Background: Many patients abandon continuous positive airway pressure (CPAP) treatment after initial acceptance. This may be for physical or psychological reasons.

Methods: We have carried out semi-structured interviews, constructed from the Health Belief Model (HBM) with a convenience sample of patients who had recently abandoned CPAP treatment after at least 6 months of use. We explored their understanding and experiences of their OSA and of the CPAP therapy and their reasons for stopping treatment.

Results: Nine patients were interviewed (age 32–70 years; 8 males). Four patients were not clear about the nature, severity, or consequences of sleep apnoea syndrome (SAS) and did not consider themselves to be ill. Three expected to be cured by the machine. Only one patient spoke of life-threatening risk. Eight of the nine patients had other health disorders. Seven stopped CPAP because of negative experiences, including problems with the mask and noise from the machine. Two patients felt 'liberated' on stopping treatment.

Conclusions: Studies at the initiation stage of CPAP treatment are needed in order to identify factors impeding acceptance, which can be addressed early. The Health Belief Model, which emphasises subjective health experience and patients' beliefs about treatment, may be a useful tool for such investigations.

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1. Introduction

The numbers of patients being diagnosed with obstructive sleep apnoea syndrome (OSAS) is rising, and continuous positive airway pressure (CPAP) therapy remains the treatment of choice [1]. Recent studies have looked at patient adherence to CPAP therapy, an important question given the tendency for patients to abandon this type of treatment [2,3]. We have found that up to 20% of our patients refuse treatment at the initiation phase, in common with other studies [4]. Our experience is that there is then a constant rate of attrition such that 30% of accepting patients will have abandoned treatment after one year of therapy (unpublished observations from AGIRadom homecare association). These figures correspond to data from recent

international studies, which indicate that rates of non-adherence to CPAP therapy range between 25–50% and that non-adherent patients typically abandon their treatment in the first few weeks of the treatment regime [5].

Poor adherence is frequently attributed to difficulties with the equipment; common reasons cited include patient discomfort with the mask, nasal dryness or congestion, as well as difficulties adapting to the pressure or the noise of the machine [3]. However, in recent years, attempts to understand patients' adherence to CPAP have widened from purely technical or physiological considerations, and it appears that psychological factors (such as emotional, cognitive or interpersonal issues) may also be predictive of adherence, as seen in other types of illness situations [6].

Psychological issues concerning patient adherence to CPAP have received limited attention to date, even though they are recognised as contributing factors in other types of treatment regimes, such as adherence to medical prescriptions or preventive health measures [7,8]. One of the key questions addressed by health psychologists is why individuals do or do not engage in a variety of health-related

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behaviours [9]. Several psychological models exist which help to explain why patients adopt (or fail to adopt) certain behaviours, which protect their health (e.g. smoking cessation or exercise) or enable them to deal with illness (e.g. modifying diet or taking medication or other therapies) [9,10]. The Health Belief Model (HBM) attempts to explain and predict patients' health behaviours by examining their attitudes and beliefs concerning their health and proposed health care interventions or therapies. This model has been developed since the 1950s [10,11]; it originally focused on patient behaviours regarding preventive health care measures (such as the uptake of screening tests), but in recent decades it has been used as a framework for exploring patient beliefs and adherence to treatments in the contexts of acute or chronic illnesses, including, for example, hypertension [12], recurrent heart failure [13] and psychiatric disorders [14]. The HBM suggests that at least three psychological factors determine the extent to which patients adopt new health behaviours or adhere to treatment regimes to improve their well-being or manage illness [10]. These three factors include the following:

- (a) the extent to which the patient considers herself or himself to be ill or vulnerable to illness;
- (b) beliefs about the benefits of adopting a prescribed health behaviour or therapy;
- (c) the extent to which the perceived effects of treatment outweigh the disadvantages.

Our study aimed to explore whether patients' beliefs and perceptions of their illness and treatment might explain their decision to abandon CPAP treatment.

OSAS is an example of a chronic illness whose ultimate effects can be dramatic, with increased risk of cardiovascular diseases and road traffic accidents [15,16]. CPAP is the main form of therapy proposed for OSAS patients. CPAP treatment can improve quality of life, survival and cardiovascular risk [17–19]; nevertheless, we have observed that many patients have difficulty adapting to this form of therapy, and some decide to give it up. While some of the physical difficulties are known (such as machine-noise and uncomfortable masks), we wondered if patients' understanding and experience of the illness and the treatment with CPAP affected their decision to abandon the therapy; such psychological dimensions as described by the HBM might help to predict adherence to CPAP and thereby aid the formulation of therapeutic strategies to help patients experiencing difficulty with CPAP treatment.

We performed this preliminary study in order to explore the extent to which psychological issues may have led OSAS patients to abandon CPAP treatment and the usefulness of this model for studying adherence. We chose to study the views and experiences of a sample of OSAS patients who had been receiving CPAP therapy for several months before they finally decided to abandon the treatment. These patients would have had some time to

experience CPAP therapy and the effects of treatment, unlike patients who had difficulties initially accepting CPAP and abandoned it within days or weeks.

2. Method

2.1. Participants

Eligible patients had to have (a) been diagnosed with OSAS by polysomnography, confirming an apnoea-hypopnoea index greater than 30 per hour of sleep; and (b) received CPAP treatment for at least 6 months and had recently decided to abandon treatment. CPAP therapy had been initiated during a 2-h session with experienced paramedical personnel at the homecare agency (AGIRadom) that is part of the French Respiratory Homecare Network (Association Nationale pour le Traitement A Domicile de l'Insuffisance Respiratoire Chronique [ANTADIR]). Patients were initially contacted by their respective sleep specialists who outlined the purpose of the study and asked if they would consent to participate in an interview with the researcher. Twenty patients were identified as meeting the inclusion criteria for the study during the 3-month period of data collection.

2.2. Tools

Patients were required to complete a mental health questionnaire, the Hospital Anxiety and Depression Scale [20], in addition to the Sleep Apnoea Quality of Life questionnaire (under validation) [21], and participate in a research interview about their OSAS and CPAP treatment. This interview was semi-structured and consisted of a series of open-ended questions that explored three dimensions within the HBM:

- (a) patients' understanding and experience of their sleep apnoea;
- (b) patients' understanding and experience of their CPAP treatment;
- (c) factors that led them to abandon the CPAP treatment.

The interview schedule was based on the HBM, and the questions were developed specifically for this study, as no disease-specific interview schedule existed for this patient group. The questions were generated during a series of research meetings involving three of the authors (JT, CP & DV) and aimed to explore the three domains outlined above; the questions retained for the interviews are listed in Table 1.

3. Procedure

The interviews were conducted in an interview room at the AGIRadom headquarters, an environment familiar to

Table 1
Outline of questions in semi-structured interview

Illness

Knowledge of illness

Does patient admit to having OSAS

Can you tell me what is OSAS for you precisely?

What are the symptoms of OSAS for you?

Can you be cured of OSAS?

Do you think you are ill with OSAS?

Do you consider yourself still concerned by OSAS?

Life with the illness

Consequences of the illness for the patient

What is the impact of this illness in your daily life?

How do you feel about these changes?

Treatment

Patients' representations of the treatment

Knowledge of the treatment

Give me details of the initiation of treatment.

What were your feelings on first seeing the machine?

Did you understand clearly about the treatment? How?

What is the purpose of the machine in your estimation?

Life with the treatment

What were your expectations of the treatment?

What differences did you feel under treatment?

Did you have any improvements, health benefits?

What difficulties were perceived during treatment?

To what degree was treatment your decision? Explain

Stopping treatment

What were motivational factors for stopping?

Tell me the reasons for stopping treatment.

Did you have particular difficulties at the time of stopping?

Did your family wish you to continue treatment?

Were your family encouraging?

What other health problems have you?

What other treatments have you?

Were there physical difficulties inciting you to stop?

Did you stop because of CPAP problems or others?

Have things changed on stopping the treatment?

Have you any worries about changing?

patients treated for OSAS. Participants completed the two questionnaires and were interviewed by the trainee research psychologist (CP) who had been involved in designing the interview schedule questions. Each interview was recorded for re-transcription and lasted about 1 h. The patient responses were subsequently classified according to the HBM grill shown in Table 1.

Data about each patient's CPAP use was available from the CPAP machine reading records, which had been routinely recorded by homecare technicians during previous home visits.

4. Results

4.1. Participants

Of the 20 patients meeting our inclusion criteria, eight lived too far away to be interviewed. Of the 12 who were invited to participate, three refused to be interviewed, and

nine patients agreed to participate in the study. Eight male and one female patient were interviewed during the 3-month study period (March–May 2004). Their ages ranged from 32 to 70 years of age (median 56 years). The number of nights equipped was between 197 and 304 (median = 239 nights), with a mean observation of 4.46 h per night.

4.2. Understanding and impact of OSAS

Patients' levels of understanding of their OSAS were highly variable, although all participants had been formally diagnosed at a sleep clinic as suffering from OSAS. Four of the nine patients were not clear about the nature or mechanisms of their sleep disorder and could only give vague explanations. All mentioned sleep disturbance or fatigue as consequences of their OSAS, which had negative effects on their daily lives (either at work, for interpersonal relations and leisure). Only one spoke of life-threatening risk. Four thought cure of the disorder was possible and five felt themselves not to be concerned by OSAS as an illness since quitting the machine, for which reason these five patients had difficulty identifying illness-related experiences.

4.3. Understanding and experience of CPAP

Patients' levels of understanding of CPAP treatment were also highly variable, despite the fact that all patients had received basic education about the treatment before embarking on CPAP therapy. Four patients mentioned difficulties with treatment, and four spoke of experiencing fatigue as a consequence of CPAP. Three patients expected to be cured by the treatment, while one declared that he had no expectations from CPAP therapy. Three mentioned a temporary benefit, which plateaued over time, and only two felt better following treatment. Many (6/9) described problems of physical discomfort associated with wearing the mask.

4.4. Decision to abandon CPAP therapy

When questioned about stopping CPAP treatment, seven specified that they did so because of their negative experiences, despite family encouragement to continue therapy in four of these cases. All nine declared that they had other health problems, and 7/9 had been prescribed other medical treatments for these conditions. Finally, five patients said that they felt better since abandoning CPAP therapy, and two specifically mentioned a sense of liberation after stopping treatment. One patient felt that stopping CPAP was a setback, and another patient expressed regrets about stopping the treatment.

4.5. Mental health questionnaire

Three patients scored over the threshold score for anxiety, and one patient scored as depressed on the HAD

questionnaire. Interestingly, the content of the interviews suggested that at least three patients were suffering from some degree of depressive symptomatology, as they made frequent references throughout the interview to poor morale and negative mood states.

5. Discussion

This preliminary study aimed to establish whether psychological issues play a role in a patient's decision to abandon CPAP therapy. Our findings are limited to nine participants who had recently abandoned CPAP treatment but indicated that their perceptions of their illness were vague and their understanding of their treatment was poor; these subjective factors may be pertinent to their decision to stop CPAP therapy.

The Health Belief Model appears to be a promising framework for exploring patients' beliefs and understandings about their health in order to understand their health behaviours (in this case, accepting or abandoning CPAP therapy). The idea of perceived costs and benefits of treatment having an influence on patients' behaviour seems to be particularly useful in understanding why this subgroup of patients gave up their treatment after several months: these patients tended to have difficulty identifying specific benefits of their treatment but had a lot to say about a wide range of drawbacks.

One unexpected finding was that these patients were not preoccupied by their sleep apnoea. It is possible that this subgroup of patients were diagnosed when their illness had little subjective perceptible effect on their lives. Furthermore, many patients appeared to be more preoccupied by other health problems, including somatic and psychological symptoms which were repeatedly mentioned during the interviews. Indeed the finding of depressive symptoms in the HAD questionnaire, as well as the reports of poor morale in several interviews, indicate that mental health issues should be considered in OSAS patients. Therefore, we suggest that patients should be more thoroughly evaluated before undergoing CPAP, (a) in order to identify those who are preoccupied by their OSAS and motivated to treat it and (b) to recognise and treat other concurrent health problems. It is possible that OSAS patients who do not perceive themselves as sick or vulnerable as a result of their sleep apnoea will be less likely to engage in a treatment regime than patients who perceive themselves as truly ill. Furthermore, the perceived benefits of CPAP treatment might be more easily appreciated by patients whose OSAS is more symptomatic than by those who have been diagnosed at earlier stages of illness.

Another issue which concerns patient expectations of CPAP treatment is that all of our patients had received information about CPAP therapy from health care staff at different stages of their care: from initial diagnosis of their OSAS, at initiation of CPAP and during clinical and

technical follow-up appointments. Our interviews revealed that within this subgroup of non-adherent patients, some expected to be cured while others attributed fatigue to the CPAP treatment itself rather than to their illness. This raises questions about their understanding of both their illness and CPAP therapy, as well as the effectiveness of the educational information currently proposed by health care staff for these individuals. We could not control or verify the quality or quantity of educational information offered to these patients, but other studies have highlighted problems concerning patient knowledge and understanding of their illness and its treatment even when information has been given by health care professionals [22].

This preliminary study raises questions about the subjective conditions under which OSAS patients embark on CPAP therapy, as well as their willingness to engage with the treatment on a long-term basis. Previous studies have examined objective characteristics such as demographic profiles, physiological data or symptom severity [23–25] in this population. The emphasis on respiratory events for evaluation of OSAS may lead to an under-evaluation of psychological aspects of the disorder and its treatment. As in other forms of chronic illness, which require long-term treatment, psychological aspects should be studied more closely. The HBM, with its emphasis on patients' beliefs and perceptions of their illness and its treatment, enables exploration of these subjective dimensions of CPAP therapy. A recent study of patient understanding of OSAS and CPAP used a new questionnaire to measure both illness and treatment [26], and indicated that patients' levels of understanding were positively associated with their attitudes to CPAP. This tool should improve the evaluation of (a) patient knowledge and beliefs about OSAS and CPAP, both of which are relevant to the HBM and (b) the extent to which these variables predict adherence to treatment with a larger sample of patients. Weaver et al. [27] have also proposed a disease-specific, self-efficacy measure for sleep apnea (SEMSA), to assess three types of adherence-related cognitions in this patient group: OSAS risk perception, outcome expectancies of CPAP, and CPAP treatment self-efficacy. The SEMSA validation study highlighted a lack of patient understanding of OSAS and the associated risks for patient health, as well as varying levels of patient motivation to engage in CPAP treatment. However, their investigation was confined to newly diagnosed OSAS patients, rather than experienced users of CPAP. Disease-specific measures such as those developed in these two recent studies should improve the preliminary psychological assessment of OSAS patients to whom CPAP is being proposed. Clinical data from these tools might also aid in the development of specific education programs to improve patient awareness and understanding of illness risks and treatment benefits; tailored educational programs can modify patients' health beliefs concerning their treatment regime [13].

We conclude that there is a need for more comprehensive psychological evaluation in conjunction with medical evaluation at the start of CPAP therapy in order to identify factors associated with successful and unsuccessful adoption of CPAP therapy. A number of psychological measures need to be studied, including subjective measures of health-related quality of life and psychopathology, as well as patient preoccupations and understanding of their illness and its management. Furthermore, patients who have already embarked on CPAP therapy and find themselves in difficulty could be more specifically evaluated in terms of their perceptions of their illness and treatment. In this way, our knowledge of factors both related to and predictive of patients' adherence to CPAP therapy should be improved.

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