

A new educational program for patients suffering from sleep apnea syndrome

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Abstract

Objective: Patients' knowledge and beliefs about their chronic illnesses such as OSAS are known to influence a range of health related variables, including treatment compliance. It is for that reason that this interdisciplinary program centred on the therapeutic education of the patients was conceived by two medical teams with the aim of creating a new coverage of the patients affected of OSAS.

Methods: Thirty-five OSAS patients were consecutively collected among those regularly followed at the Service of pneumology outpatient facility. The psycho-educational methodology as well as the courses are described in detail. Patients were admitted for 36 h at the Service of Therapeutic Education for Chronic Diseases for both individual and group multidisciplinary approach to their disease. Groups of 3–4 patients discuss benefits, inconvenience as well as CPAP representations and manipulation of the device in small workshops.

Results: The therapeutic objectives, the educational methods, the program evaluation are presented. Preliminary results show a clinical improvement of the duration of CPAP use (0.7 ± 0.2 h/night). 24% of patients increased the CPAP use more than one hour per night 3 months later. The Epworth sleepiness scale is significantly improved 3 months later ($p < 0.05$).

Conclusion: We describe a new therapeutic educational interdisciplinary program for patients affected by OSAS. Its efficacy will be tested prospectively in a larger group and in the long term.

Practice implications: The educational methods were applicable to the patients affected of OSAS bringing new specific strategies to improve the CPAP use.

Patients had a positive attitude towards the CPAP treatment.

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1. Introduction

Nasal continuous positive airway pressure (CPAP) – night treatment by means of an artificial respiration with positive pressure- device is the top-grade treatment of the obstructive sleep apnea syndrome (OSAS). The CPAP is very effective both abolishing the obstructive apneas and decreasing related symptoms [1–3]. Our capacity to treat

effectively all the patients affected by OSAS is limited largely however by a compliance issue which is well known by all the nursing staff taking care of chronic diseases.

Knowing that it is at present well established that the improvement of the symptoms of OSAS is proportionally correlated in the duration of use of the device [4,5,23–25], it becomes obvious that the improvement of the adherence of the patients to their treatment is of major importance.

OSAS treatment efficacy is inferior to that of asthma or arterial high blood pressure [6,7] basically due to a lack of adherence in the use of the CPAP [8–10]. Approximately

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Table 1
Obstacles to the use of the CPAP

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- Night-intimacy: the night-treatment provokes difficulties in the intimacy of the couple, on one's self-image
 - Noise: the patient, that does not perceive his own snores, is bothered by the noise of the machine, although this last one is very discreet and on any account comparable to the noise of snores
 - Dependence-chronicity: dependence on a machine and a long-term treatment
 - Non-understanding: the patient does not perceive the reason for which he should be treated. He does not feel sick
 - Cost-benefits: for the patients not conscious of the symptoms of OSAS, the CPAP appears as a big constraint for few benefits
 - Tolerance in the treatment: the patients complain of some inconveniences related to the use of the CPAP (cold air, dry nose, etc.)
-

one out of two patients affected by OSAS and therefore elective candidate to CPAP treatment, uses the prescribed device [11]. Among those who accept its usage, most will drop out during 6 first months [12]. And for those who continue using it, 20–30% of them employ it insufficiently [13,14].

The role of the therapeutic education to improve the acceptance and the observance of the CPAP had only received modest attention until now. Likar et al. showed that a therapeutic education of 2 h every 6 months allows to increase the duration of the CPAP use of at least 1 h during the night for more than 90% of the patients [15]. More recently Hoy et al. [16] compared prospectively the observance in two randomised groups. The one benefiting from a “standard” coverage, and the other one of an “extensive” coverage. The latter was a therapeutic education at home with the spouse, house calls repeated by specialized nurses and three nights of CPAP testing at the hospital. The duration of use of the CPAP in the group benefiting from the intervention was of 5.4 versus 3.8 h in the control group. This study shows in a clear way for the first time that a modification of the coverage ended in an improvement of the therapeutic observance of the CPAP. The results of these two studies indicate that the way of the education for the patients affected by OSAS should be emphasized. In this purpose, we developed a program of interdisciplinary therapeutic education for patients suffering from the OSAS requiring a treatment by means of a CPAP.

2. Material and methods

Patients were consecutively collected among those regularly followed at the Respiratory Care Division (RCD) Outpatient facility. Written informed consent was obtained from all participants. The University of Geneva Cantonal Hospital ethical committee approved the protocol. Inclusion criteria were: men and women being affected by OSAS, according to the following: Apnea-Hypopnea index > 5 during overnight polysomnography and currently on CPAP therapy for the last 6 months.

The RCD team elaborated a consensus regarding the problems induced by OSAS and by the use of CPAP. These difficulties were classified by subjects, which allowed the build-up of various workshops, establishing the base of our program.

Some difficulties were highlighted during visual discussion about OSAS and its treatment. They concerned both patients and health care providers.

The initiative to attend the consultation results mostly from the spouse because the patient is not motivated himself. Indeed, the couple encounters difficulties in their intimacy.

Furthermore, many patients hope to get cured and hence, to stop CPAP treatment. A large number of them consult a surgeon at first.

Finally, the health care providers except the physiotherapists have not enough experience with devices. The difficulties were identified by a visual discussion by using the technique of Metaplan [17]—an open discussion using several lists of items posted on a board- and were able to be gathered together in 6 categories which are described in Table 1.

2.1. Determination of the subjects to develop in the program

When encountering difficulties, the first proposition of the nurse is to explain to the patients their disease (OSAS) so that they understand the usefulness of being treated, leaving the principle that the better the patient understands, the better she/he will follow her/his treatment. This assertion is certainly not false, but does not constitute the dominant motivation of the adherence to the treatment. To avoid being centred on the disease and the device, we suggested a “patient-centred” approach. Therefore, a brief – 6 topics – handout was elaborated by the members of the RDC and Service of Therapeutic Education for Chronic Diseases (STECD) to be used in the program of therapeutic education (Table 2).

2.2. The therapeutic education program

The program, shown in Table 3, was basically inspired by structures already conceived by other outpatient programs of

Table 2
Workshops and round tables

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- What does CPAP serve for?
 - How to use the CPAP?
 - The benefits of CPAP
 - The daily life with the CPAP and its disadvantages
 - What I can do myself and my representations
 - Round Table with the spouses: my intimacy and my CPAP
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Table 3

Educational program description

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- Reception of the patients: the program of the day as well as both teams are presented; the patient's expectations are spoken out loudly
 - Anamnesis in binomial of every single patient
 - Open doors workshops on the manipulation of the device in parallel to anamneses
 - Course "What does CPAP serve for?"
 - Team discussion regarding the specific objectives for every patient
 - Two sessions of workshops in parallel with choice in small groups, according to the objectives and patient's own choices
 - ENT Consultation for those patients who deserve it
 - Round Table with the spouses
 - Installation for night
 - "How did the patient spend the night?"
 - Discharge interview after breakfast made by same binomial of health care providers in order to synthesize the main conclusion of the program
-

the STECD to organize the chronology of the activities and choose the educational methods.

The treatment by CPAP being at night, the patients stayed one night at a hospital environment to perform the CPAP titration sleep study. During the night, the observance was evaluated by the number of hours using the CPAP.

The welcoming of the patients is hosted by the two doctors responsible for the division of Pneumology (RDC) and the STECD, respectively. The schedule of the day is presented and both teams of health care providers are introduced to the patients. Patients are encouraged to fully express their own expectations of the program.

Later on, patients undergo a binomial anamnesis: every patient is seen by a binomial established by both teams for a full history targeted at his symptoms, treatments, expectations and difficulties with regard to this program.

In the meantime, patients who are not seen in binomial (or who were already interviewed), participate in an "open doors" workshop focused on the manipulation of the CPAP device. Every patient comes with his device and should dismantle it, clean it and raise it up, in the presence of the physiotherapist who observes and comments on the activities.

A course entitled "What does CPAP serve for?" is followed by all the patients at a time. Explanations on OSAS nature are provided, with demonstrations on the utility of a CPAP.

The discussion of both teams about the specific objectives determined for every patient, from the observations made during the anamnesis, during the class and during the workshop, is going to allow every patient to choose the two workshops of the afternoon, which are most suitable to them. At least three patients are assigned by workshop while two sessions of two workshops in parallel are organized and the patients are separate in two groups, according to the topics of the workshops.

An Ear Nose and Throat (ENT) consultation is provided for those patients who, according to both medical teams deserve it.

A round table with the spouses/husbands, conceived to favour an exchange around the advantages and the disadvantages of the CPAP in the life of the couple, takes place in the evening. It is co-chaired by a psychologist and a

respiratory medicine specialist. The dimension "couples" is emphasised because the main complaint often comes from the spouse, and because the bearing of the CPAP device overnight brings difficulties in their intimacy.

The observations made during day are reported to the night-shift nursing team (a nursing respiratory care specialist and the night-shift nurse).

The observations of the night-shift nurses are transmitted to the day-shift nurse and the physiotherapist of every patient, with statement of the number of hours of use.

Patients are discharge after breakfast following an interview with the same binomial of health care providers. A medical report is regularly released to their regular general practitioner.

2.3. Description of the courses and the workshops

2.3.1. What does the CPAP serve for?

We wish that the patients understand why they snore and make apneas and how the CPAP abolishes fatigue and slumber. The specific objectives of this course are to understand the word apnea, some symptoms of the disease, the mechanisms of the disease and its treatment by the CPAP. The patients are invited to enumerate the symptoms that they attribute to OSAS. The health care provider establishes the list on the board, by separating the respiratory symptoms connected to the apneas of those bound to the confusions of the sleep. This list is used as an introduction to explain the disease and ask the patients about the consequences, which they consider. The patients are also encouraged to express what they know about the disease and about the treatment.

In the second time, a video is presented which shows a patient affected of OSAS, who snores and makes respiratory pauses accompanied with movements of fight. The anatomy of the larynx is explained through illustrations and the mechanism of apneas is illustrated. The course ends with the review of the definition of OSAS and apneas.

2.3.2. How to use the CPAP

The objective of this workshop is to practice the manipulations of the device and its accessories which the patients should regularly execute at home. For that purpose,

every patient dismantle himself his device, washes each piece of the CPAP, exercises to change filters if necessary, then goes back to assemble the device. The physiotherapist comments on the manipulations and checks the knowledge of the patient, observes all these activities. A plan describing the inside of a CPAP and a summary of the tasks of maintenance of the device and its accessories is distributed at the end of workshop.

2.3.3. *The benefits of the CPAP*

The objectives of this workshop are to allow the patients to identify the symptoms related to OSAS and the importance of the evaluation after their symptoms. The workshop begins with a free discussion by asking the patients to describe their symptoms that they attribute to OSAS as well as benefits felt after the use of the CPAP. It is important, during the constitution of the group of patients who will follow this workshop, to register one or two patients who have already clearly expressed benefits linked to the use of the CPAP. Their experience can then help other patients to consider a utility in the treatment. At the end of workshop, a list of 22 possible consequences of the disease is distributed to the patients. Patients are then asked to choose three situations, which correspond to them best. A score is attributed to each of these propositions, by a scale from 0 to 10, allowing the health care provider to follow the evolution of the efficacy of the treatment, according to the application of the treatment (Table 4).

2.3.4. *The daily life with the CPAP and its disadvantages*

This workshop aims at identifying for every patient the inconveniences felt during the use of the CPAP, at identifying the technical problems in the daily life and at finding solutions being able to solve it. The discussion is launched on the inconveniences, which the patients feel and attributed to the CPAP. In the second time, patients are asked to find means to remedy it. Following their appropriate strategies a discussion takes place around various objects (humidifier, nasal cream, chin strap, etc.). A list of the symptoms and their solutions is distributed at the end of the workshop (Table 5).

2.3.5. *What can do myself and my representations*

The objective of this workshop is to identify the obstacles to follow CPAP treatment resulting from representations that the patients have made on their disease and its treatment. By favouring the expression of the patient on the representations of the disease and its treatment, it is easier to confront them to the medical knowledge and to arouse the awareness of the patient to the role they can play to decrease the deteriorating factors. The workshop begins with an exercise of photo-language. By asking the patients to choose among the images displayed on a table, they can represent themselves a treatment, which could be effective in case CPAP treatment should fail. Every patient explains to the others what the picture represents for him and the reasons of his/her choice.

Table 4
Auto evaluation of the efficacy of the treatment by CPAP

Please, choose the three main problems, which correspond to you most, which you can underline in this list. Then, determine the severity on a scale between 1 and 10 (extremely annoying problem: score 10, not annoying problem: score 0). Please, register this score in the column on the date of the evaluation

	Date	Date	Date	Date	Date	Date
The consequences of the disease to me						
-Fatigue
-Slumberness
-Memory troubles
-Concentration troubles
-Libido problems
-Dynamism
-Professional performances
-Sentimental relationships
-Family relationships
-Friendly relationships
-Professional relationships
-Cardiovascular risks
-Financial problems
-Others
The consequences of the disease to my spouse						
-Restless nights.
-Separate rooms
-Relational
-Image he/she has of me
-Others
The consequences of the disease to my family						
-Relational
-Image he/she has of me
-Others
The consequences of the disease to society						
-Traffic accidents
-Professional accidents
-Inactivity
-Others
The score can be periodically re-evaluated. It is going to help you estimate the benefit of the treatment, which you are currently following						

A confrontation between the assertions of the patients and the medical knowledge on the controversial subjects takes place. The purpose is to identify the most important propositions for the patient, to strengthen those who are positive. A summary table of the recommended, contra-indicated treatments and the alternative medicines is distributed at the end of workshop (Table 6).

2.3.6. *Round table with the spouses: my intimacy and my CPAP*

The general objective of this round table is to help the patient to accept the intervention of the CPAP in his daily life and in his intimacy. A discussion is held on the patients' experience; patients are asked to describe the reasons for which they consulted for the first time. The word is then given to the spouses to have their testimony. The purpose is to help the patients to become aware of symptoms from which they suffer, even if they are not completely conscious

Table 5

The various types of inconveniences bound to the use of the CPAP and some possible solutions

Irritation and/or cutaneous erosion	
<ul style="list-style-type: none"> • Improve the regulations of the mask, the tension of belts • Change the zones of support • Change model of mask • Vinyl mask if allergy to the silicone • Temporary interruption of the treatment if EROSION • Varihésive IF EROSION • Molded mask 	
Dryness nose/mouth	
<ul style="list-style-type: none"> • Neutral cream HCZ • Bépanthène[®] nasal cream • Humidifier with cold air • Humidifier with warm air 	
Nasal drainage	
<ul style="list-style-type: none"> • Neutral cream typifies HCZ • Steroids in spray in pomade • Humidifier with cold air • Humidifier with warm air • Otrinol[®] or Contac[®] (=pseudoéphédrine delay in po tablet, with effects lasting 12 h approximately) except when hypertension 	
Air leak to the mouth:	
<ul style="list-style-type: none"> • Cervical necklace • Chin strap • Other type of ventilation, as BiPAP[®], and full-mask 	
Red eyes	
<ul style="list-style-type: none"> • Modification of the regulations of the mask (if possible) • Different mask size • Comfortflap if Respiroics[®] masks • Change of type of mask 	
Noise	
<ul style="list-style-type: none"> • Councils of installation (position of the CPAP, the quality of the support, add a pipe) • Change of device (more recent model, Somnotron) • CPAP settlement in the vicinity room through a hole in the wall 	

of them. The experience with the machine is then discussed and launched by the questions: “how do you bear this machine, how do you live with it?” “And what does your partner think of it? Did life change, and how?” The favourable and unfavourable points are shared in-group and

Table 6

“What I can do myself”

Recommended treatments	Indication
CPAP	All the suffering patients of apnea of the sleep
Regularity within hours of bedtime and to raise	All the suffering patients of sleep apnea syndrome
To sleep on the side	The patients who sleep on the back
Surgery	Some patients with (rare) particular anatomical problems
Maxillary orthosis	Some patients with (rare) particular anatomical problems
Loss of weight	Some obese patients can do without the CPAP having lost weight
Physical exercise	Excessive body weight, sedentary way of life, difficulty of falling asleep in the evening
To limit alcoholic drinks: no more than 3 drinks/day, not to drink in the evening.	The patients who drink alcohol in the evening since alcohol interferes with breath commands
Discontinue sleeping drugs (replaced by technique of relaxation, physical exercise in the evening)	Patients who take sleeping drugs because they put to sleep the command of the breath

with the spouses. The purpose here is to put in balance the inconveniences and the advantages of the CPAP. This type of discussion aims at allowing the patients to express their thoughts, but especially to confront them to those of the other patients. Realizing problems of the others allow patients not feeling isolated and favours the expression of individual difficulties. The testimony of a positive experience of one of the participants allows the others to consider another way of behaving. “Tricks” are exchanged, hypotheses established. The leading part of the psychologists is to favour the exchange among the patients and to highlight the key points which stand out from it. The workshop also aims at making patients become aware of the four stages of the Health Beliefs Model [18] that is to say:

1. They are sick, even if the symptoms of OSAS are discreet.
2. OSAS is a disease, which can have serious repercussions on their health.
3. A treatment exists and the CPAP is effective.
4. The inconveniences of the treatment are weaker than benefits to be removed from it. As long as a patient is not convinced by the truthfulness of these 4 assertions, his adherence to the treatment cannot be optimal.

2.4. Program evaluation

We chose to define the program evaluation as the repercussions that this therapeutic education program has on the patients and on the qualitative evaluation of the classes given to them. Therefore three main issues have been prospectively addressed: (1) the reading of CPAP meters, (2) slumber evolution (assessed by Epworth’s scores) [19] and (3) the quality of life assessed by the SF36 [20].

Concerning the repercussions of the program on the adherence to the treatment, we chose to read the meters of the CPAP, which indicates the number of hours when the device was in use and which is noted in the outpatient consultations before the program (baseline), at the conclusion of the night spent in the therapeutic teaching unit (night #1) and in the follow-up visits in 3 months.

Table 7
Epworth sleepiness scale (ESS)

Name and first name: _____
 Date: _____ Your age (years): _____
 Sex (Female = F, Male = M): _____

What are your chances of falling asleep in the following situations, in contrast with a simple feeling of tiredness? This refers to your usual way of life lately. Even if you were not confronted with these situations recently, try to imagine to which point these situations would allocate you. Please, use the following scale to choose the most suited figure for every situation.

0 = no chances of slumbering
 1 = weak chances of slumbering
 2 = moderate chances of slumbering
 3 = strong chances of slumbering

Situations	Slumbering chances
1. -Being seated while reading:	_____
2. -Watching TV:	_____
3. -Being seated, inactively, in a public place (i.e. theatre, meeting):	_____
4. -Being a passenger in a car for a non-stop ride longer than 1 hour:	_____
5. -Lying down to have a rest in the afternoon:	_____
6. -Being seated and talk to somebody:	_____
7. -Being seated calmly after a meal without alcohol:	_____
8. -Being stuck in your car for a few minutes (i.e. traffic jam)	_____

Thank you for your cooperation

Score (Sum of the 8 issues) _____ (0 to 24)

Epworth’s score (Table 7) is also calculated at these same occasions. It consists of an itemized questionnaire [19] which allows estimating the symptoms of slumber of the patients. Since the score has a proven correlation to the gravity of ITS [21] it serves as an indicator of OSAS clinical improvement by means of the CPAP treatment.

However, by listening to some comments of the patients such as the importance to share experiences among peers or not to feel any more isolated in the experience of the disease or the treatment, it seemed to us that this program could also touch other parameters than adherence to the treatment. Thus, we added the questionnaire on the quality of life SF36, which the patients filled during the therapeutic education program as well as in the visits in 3 months [20].

Finally, the educational competence of the nurses was assessed by video-recording of the classes, the tool developed and validated by our group [22]. This evaluation is formative and is made from the video recording of the classes.

3. Results

Patients: Table 8 depicts the main characteristics of the patient population which participated in the study. As

shown, patients were in the mid fifties and men outnumbered women in a 2:1 ratio. By definition, all of them were affected by OSAS. The latter was diagnosed by overnight polysomnography (apnea-hypopnea index). According to HAI average (49.7 ± 4.7), OSAS is characterized as being severe. Additionally, they reported being on nasal CPAP treatment for

Table 8
Preliminary results

	Before	After 3 months
Number of patients (M/F)	35 (22 M – 13 F)	
Age (Y)	58.3 ± 1.9	
Body mass index (kg/m ²)	34.9 ± 1.1	
Apnea-hypopnea index (HAI)	49.7 ± 4.7	
Desaturation index (IED)	32.7 ± 3.5	
CPAP treatment duration (days)	323 ± 62	
CPAP pressure (cm H ₂ O)	8.6 ± 0.7	
Epworth score	11 ± 1	8 ± 0.8 (p < 0.05)
Compliance (h)	4.4 ± 0.3	5.1 ± 0.4
Physical functioning	60.3 ± 5.5	68.0 ± 4.0
Role-physical	61.6 ± 7.1	64.3 ± 8.0
Bodily pain	89.9 ± 2.2	85.5 ± 3.0
General health	61.4 ± 4.5	58.4 ± 4.4
Vitality	50.7 ± 4.1	44.8 ± 3.7
Social functioning	67.4 ± 5.5	66.1 ± 4.9
Role emotional	71.4 ± 7.6	66.7 ± 7.3
Mental health	68.0 ± 4.2	61.1 ± 3.9

an average of less than one year. Baseline CPAP readings were low. Interestingly enough, 15% of them were still active smokers.

Body mass indexes mean was well in the pre-morbid range ($34.9 \pm 1.1 \text{ kg/m}^2$). Type 2 Diabetes mellitus was found in 45% of the patients, while Dyslipidemia and Hypertension were found to be 55 and 43%, respectively. Baseline CPAP readings averaged $4.4 \pm 0.3 \text{ h}$ while the readings raised to $5.1 \pm 0.4 \text{ h}$ after 3 months. 24% of patients increased the CPAP use more than 1 h per night.

Baseline Epworth score is depicted in Table 8 (11 ± 1). Three months after patient education significant improvement is detected (8 ± 0.8) ($p < 0.05$). All the subscores from the SF36 are represented in Table 8. Three months after patient education no significant improvement could be detected.

4. Discussion and conclusion

4.1. Discussion

Patients' knowledge and beliefs about their illnesses are known to influence a range of health related variables, including treatment compliance. It may, therefore, be important to quantify these variables to assess their impact on compliance, particularly in chronic illnesses such as OSAS that rely on self-administered treatments [16,23–25]. It is for that reason that this interdisciplinary program centred on the therapeutic education of the patients was conceived by two medical teams with the aim of creating a new coverage of the patients affected of OSAS. In this article, the therapeutic objectives, the educational methods, the program evaluation as well as the preliminary results are presented. The aim is building up an analysable and reproducible program.

Our preliminary results disclose our OSAS population presenting particularly classical features of the insulin resistance syndrome including pre-morbid obesities in association with diabetes, hypertension and dyslipidemia. The latter is not unusual and has already been described [2,23]. Additionally the Epworth scale's mean is in the high side probably translating the presence of slumber. Additionally, baseline CPAP readings were low, again in accordance with the anthropometrical characteristics of the patients and their Epworth scale's mean.

Although it is still too early to be able to interpret the results of this program, the preliminary results at our arrangement show an improvement of the duration of use of the CPAP about $0.7 \pm 0.2 \text{ h}$ by patient and on night on average. It will be of major interest to have CPAP readings, Epworth scales and SF-36 values in a larger group and in the long term.

Moreover, the collaboration between both teams is unanimously lived as a source of renewal, progress and enrichment. For the Respiratory Care Nursing staff, it is an

occasion to form in therapeutic education, with the supervision of nursing experts in this domain. This formal training can be useful for them in the follow-up of their patients. For the Service to Therapeutic Education for Chronic Diseases, the confrontation with a still unexplored therapeutic domain allowed to notice that the educational methods used until then were applicable to the patients that must be treated by CPAP, while bringing new more specific strategies to this type of patients. The enthusiasm of some as is the others an encouraging signal to develop the other associations, the field of the chronic diseases being able to benefit from an educational approach being still vast.

4.2. Conclusion

In conclusion, although it is still too early to be able to interpret the results of this program, the preliminary results show an improvement of the duration of CPAP use more than one hour per night in 24% of patients and Epworth sleepiness scale improved significantly. The collaboration between both teams is unanimously lived as a source of renewal, progress and enrichment.

4.3. Practice implications

The educational methods were applicable to the patients affected of OSAS bringing new specific strategies to improve the CPAP use. Patients had a positive attitude towards the CPAP treatment.

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