

Impact, Perception, Role and Expectations of Sleep Partners of Patients Suffering from Sleep Apnea Syndrome and Treated at Home by CPAP: Results of a Large Scale Study of More than 900 Patients

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Abstract: *Objective:* Sleep apnea is a breathing disorder requiring treatment by CPAP. The impact of sleep apnea and how the condition and its treatment are perceived by partners have been studied in small populations. However, few large scale studies have focused on the role and expectations of partners of patients treated with CPAP.

Methods: descriptive study of responses to questionnaires sent to 2,059 patients treated for Sleep apnea by CPAP for 6 months and to their partners.

Results: 922 questionnaires returned by patients, 673 by partners. 37% sought medical help for the first time upon the partner's initiative. Male patients evoke the breathing pauses occurring at night reported by their partner and a decrease in sexual activity. Female patients focus more on the quality of sleep, tiredness and signs relating to depression. Male patients were more often accompanied by their sleep partner than female patients. For 80% of patients, the partner had a positive effect on initiation of the treatment. Sleep partners talk openly with the patients about the treatment (93%) and encourage them to continue with it (93%). For sleep partners, the benefits of treatment are essentially felt with respect to the quality of sleep. Overall, the benefits of the treatment outweigh the constraints.

Conclusions: Sleep apnea and CPAP undoubtedly have an effect on partners. The latter play an important role in the initiation and continuation of the treatment.

Practice Implications: Patients and partners have specific expectations which must be taken into account by doctors and Home Care Providers.

Keywords: Sleep apnea syndrome, CPAP, partners, impact, role, expectations, Home Care Providers, specialists.

1. INTRODUCTION

Sleep Apnea Syndrome is a disorder characterized by recurrent nocturnal episodes of apnea and hyperpnoea leading to desaturation and micro-arousal. A strong correlation has been established between SLEEP APNOEA SYNDROME and the risk to health (notably cardiovascular risk, risk of road accidents following sudden sleepiness, etc.) [1]. In France, patients suffering from this type of sleep-related breathing disorder are managed by the lung specialist.

These patients, who are often snorers, also suffer from day-time sleepiness, morning headaches and tiredness, but may also present with more obvious signs and it is often the sleep partner, alerted by the excessively loud and heavy snoring and/or periods of breathing cessation during sleep, who seeks medical advice first.

It is believed that SLEEP APNOEA SYNDROME affects almost 2% of women and 4% of men [2]. As SLEEP APNOEA SYNDROME is related to obesity and to metabolic syndrome, and given the epidemiological increase in this type of disorder, it is clear that more and more patients will be affected by SLEEP APNOEA SYNDROME in the years to come [3] and [4]. The preferred treatment for SLEEP APNOEA SYNDROME today is home ventilation by means of a Continuous Positive Airway Pressure (CPAP) device, which is only effective if used for 4 to 5 hours per day.

Within this context, studies have effectively demonstrated the impact of the disease and treatment on the quality of life of patients and their sleep partners [5] and [6]. Parish and Lyng [7] studied the effect of the disease and of CPAP treatment on 54 patients and their sleep partners. They found that while the disease had a clearly negative impact on the quality of life of patients and their partners, CPAP treatment had a rather positive effect. Other studies have also analyzed

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the effect of the disease on the sleep partner [6] with regard to sleep disturbance [8] and quality of life [9-11].

Few studies, however, have focused on the perception, expectations and above all the role played throughout treatment by those close to patients with SLEEP APNOEA SYNDROME and treated by CPAP, on a large number of patients. The objectives of this large scale study of more than 900 patients and sleep partners are to describe the differences in perception between patients and their partners, to more effectively analyze expectations and to clearly define the role played by sleep partners in the acceptance of the disease and its treatment. The scope of the study will make it possible to describe more specifically the role played by the family circle in caring for SLEEP APNOEA SYNDROME sufferers.

2. MATERIALS AND METHODS

The study was carried out on patients suffering from SLEEP APNOEA SYNDROME who had been fitted with a CPAP device more than 6 months previously. All patients underwent respiratory polygraphy (and polysomnography if doubt persisted) to establish the diagnosis (Index of apnea/hypopnea > 30/h) and, after a pressure titration phase with an AutoSet machine and therapeutic education, were regularly monitored by their specialist (5 months after the CPAP device was fitted then every year) and by a technician from the Home Care Provider service (within the first month after fitting, four months later, then every six months). The patients were monitored by various sleep centers (community or hospital-based). 2,059 questionnaires were sent by post in the summer of 2006 to patients and to their partners where appropriate (a copy of the questionnaire is presented

in the annexes). This was a multiple choice questionnaire. A crossover statistical analysis and a Chi2 significance test were performed on the completed questionnaires.

3. RESULTS

922 questionnaires were returned by patients and 673 by their partners.

3.1. Patient Profile (Table 1)

The patient profile is based on answers from the questionnaire only.

Patients suffering from SLEEP APNOEA SYNDROME and treated by CPAP are, for the main part, retired (64%), male (76%) and of an average age of 64 years (only 11% of patients are under 50). Sleep partners are mainly female (79%), of an average age of 61 years and mainly retired (see Table 1).

81% do not live alone, 97% have a sleep partner and 29% have children living at home. 19% of patients live alone and have done so for 13 years on average; a situation which, according to the patients, is not necessarily related to their condition or its treatment (this only applies to 11% of patients). Women were found to live alone more frequently than men (Women: 35% vs. Men: 14%, $p < 0.001$). The patients had been receiving CPAP treatment for 3 or 4 years on average (3/4 have had the device for more than a year).

3.2. Origin and Initiation of Treatment

Before treatment was started, only 1/3 of patients were aware that they had SLEEP APNOEA SYNDROME and

Table 1. Population of Patients and Sleep Partners

Feature	Value
Sex	
Male	76 %
Female	24%
Age	64 years on average (sleep partners 61 years)
Smoker	12 % (sleep partner 11%)
Living	
With a sleep partner or other partner	81 % (97% sleep partner with 29% children at home)
Alone	19%
Length of treatment	3.4 years (average)
Less than a year	23%
1-3 years	42%
4-10 years	33%
> 10 years	2%
Socioprofessional activity	
Retired	64% (sleep partners 55%)
Non-executive managers	9% (sleep partners 15%)
Executive managers	9% (sleep partners 5%)
Worker	5% (sleep partners 3%)
Unemployed	4% (sleep partners 12%)
Others	10% (sleep partners 10%)

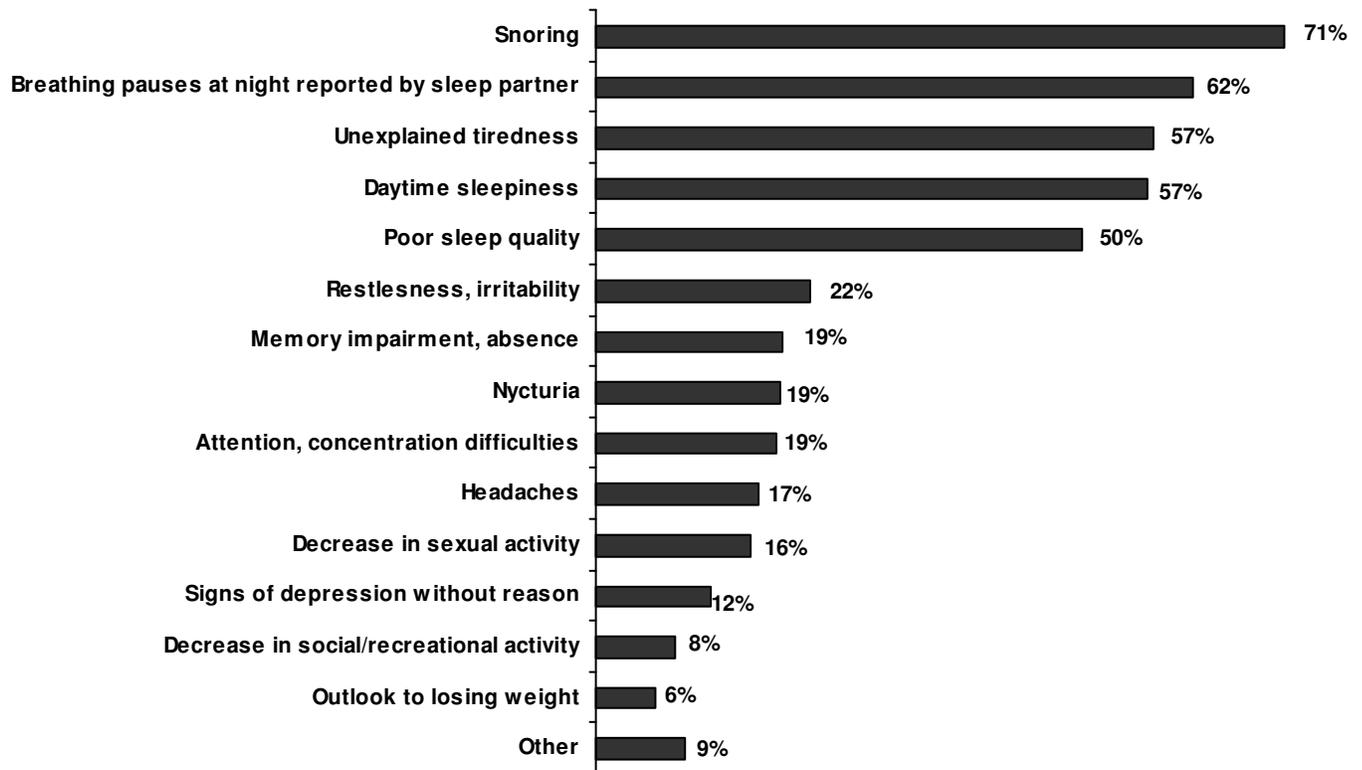


Fig. (1). Patients' symptoms leading to consultation.

only 17% had heard about CPAP treatment. Professional medical advice is often sought for the first time following referral by the general practitioner but the sleep partner also played an important role (instigator in 37% of cases), especially with respect to male patients (41%). Only 21% of patients sought medical advice on their own initiative.

The symptoms having prompted consultation with a doctor were essentially related to sleep and tiredness: on average, patients sought medical advice because of 4 to 5 symptoms (Fig. 1). Slight differences arise depending on sex: men mainly describe nocturnal breathing pauses (most frequently reported by their sleep partner) and a decrease in sexual activity, whereas women are more sensitive to the quality of sleep, to tiredness and to signs related to depression ($p < 0.005$).

For 74% of patients, the family circle's reaction to sleep recording at home was positive. Almost half of patients' sleep partners were not present when the diagnosis was announced. A higher proportion of women attended their appointment alone (Women: 42% vs. 55%. $p < 0.003$).

Information relating to SLEEP APNOEA SYNDROME and CPAP was provided essentially by the medical profession. Both the patients and their sleep partners obtained additional information from their general practitioner (more than 70%). Internet sites are used by 9% of patients, although this percentage is slightly higher amongst younger subjects (15%). For 80% of patients, partners were seen to have a positive influence on CPAP use.

3.3. Treatment Monitoring

61% of patients felt their general practitioner played a positive role in treatment monitoring (vs. 3% negative), but that the role played by family members was more significant.

The treatment provided relief for 44% of patients, with 72% reporting a feeling of well-being, "I'm fine", and 40% getting more out of life. Patients reported an improvement in quality of life resulting from a more positive "psychological state":

- feeling worn out: 29% decrease
- restlessness: 22% decrease
- anxiety: 18% decrease
- depression: 14% decrease

and also evoked a rise in both social and marital satisfaction.

The benefits of treatment are essentially felt as regards the quality of the patient's sleep, but also that of the sleep partner. The positive effects on the family, in the home and at work are less marked. 91% of patients find that they have a good quality of life (96% for sleep partners).

CPAP is considered to be reliable, easy to maintain and handle, but is criticized for its unsightly appearance and noise level. Overall, the benefits of the treatment outweigh the constraints for 87% of patients and 94% of sleep partners.

Sleep partners talk openly with the patient about treatment (93%) and encourage the patient to continue (93%). They also help the patient to maintain appropriate dietary habits (75%). Anxiety, discomfort and constraints relating to the disorder / treatment are the most sensitive subjects for couples (almost 50% do not talk about them). Men are more effectively supported by their partner than women.

Both patients and sleep partners expect to receive comprehensive information concerning the disease and its treatment (duration, adjustments and side effects) and to a lesser

Table 2. What Patient Felt Hey Need with Respect to the Doctor and the Home Care Provider

	Patient	Partner	Patient	Partner
Detailed explanations concerning the disease	35%	40%	15%	16%
More information on treatment	28%	31%	22%	20%
More information on mask CPAP	19%	16%	53%	46%
More information concerning the benefits of the treatment (on driving for example)	24%	24%	21%	20%
More information concerning the consequences of not treating the disease (hypertension, heart attack for example)	48%	49%	23%	23%
More information on treatment adjustment	43%	57%	35%	40%
Assistance with respect to dietary habits	33%	32%	13%	13%
Contact with other patients or associations	5%	5%	7%	7%
Psychological assistance and support	8%	5%	4%	4%
More information concerning administrative aspects	7%	8%	17%	17%
More personalised care taking into account my difficulties and my way of life	11%	9%	12%	7%
Improved communication and more information for my family doctor	17%	20%	13%	12%
More information concerning the possible side effects and treatment	36%	36%	38%	42%
More information concerning the lifestyle changes to be made (diet, exercise)	24%	22%	15%	15%
Increased transparency as to length of treatment	48%	43%	29%	32%
Increased involvement of my partner at the time of diagnosis and/or upon implementation of the treatment	5%	12%	5%	10%
Others	2%	3%	6%	3%

extent concerning dietary habits (see Table 2). Expectations with respect to the Home Care Provider are different: patients expect to receive information concerning the CPAP device and masks. Patients also expect to receive information concerning the treatment (duration, adjustments and side effects (see Table 2)).

4. DISCUSSION

This large scale study, the first of its type in terms of the number of patients and sleep partners questioned, highlights the importance of the role of the patient's family circle both in detecting and diagnosing SLEEP APNOEA SYNDROME through observation, but also in the acceptance, monitoring and help in evaluating the efficacy of CPAP for patients suffering from SLEEP APNOEA SYNDROME. The relevance of "Global Disease Management" and of therapeutic education for patients has increased over the last few years. Can the patient still be associated with his family circle where his health is concerned and where disease management may prove to be complex? Despite methodological bias, several elements emerge concerning the role played by the sleep partner in the management of the disease and underline the need for their closer involvement in caring for patients.

At Diagnosis and Upon Treatment Initiation

The majority of patients are male, aged over 60 years old, are retired and mostly live with a partner (with or without children); this type of device inevitably therefore has an effect on the relationship. In an altogether surprising manner,

however, the sleep partner appears to exert a strong influence with respect to acceptance of the disease (i.e. in recognizing that the specific symptoms, which may appear to be insignificant, represent a serious medical concern) and its treatment by the patient. A significant proportion of patients (more than one third) sought medical advice at the request of the partner. This is notably the case of the many patients for whom the symptoms are sleep-related (snoring and nocturnal apnea) and which are not noticed by the patients themselves. Male patients tend to rely more on their sleep partner when managing the disease and half of them attended their appointment with this partner. Patients also refer to the positive role played by their family circle during the diagnostic tests. The family circle's contribution to the care of patients suffering from SLEEP APNOEA SYNDROME, especially at the start but also during CPAP treatment, appears to be essential in daily practice.

The different male/female perceptions of the disease and of the treatment must be taken into account if it is to be managed as effectively as possible. Men tend to focus on the breathing pauses at night as described by their sleep partner and on decreased in sexual activity; women are more sensitive to quality of sleep, tiredness and signs related to depression. These different perceptions should be interpreted by the doctor and the Home Care Provider in such a way so as to effectively manage care, which in the long run, can sometimes prove to be complex. Patients tended to describe 4 to 5 different symptoms during the appointment.

On Starting and Pursuing Treatment

Patients clearly state that their general practitioner played a positive role even if his/her influence was less positive than that of the family circle. In actual fact, allowing the sleep partner to talk more freely about the effects of the disorder, and above all of the CPAP device, on the couple must be seen as a way of dealing with certain issues. Despite the impact of this type of treatment on the relationship, the sleep partner is known to play an essential role – especially when the patient continues to use the device. Finally the expectations of patients and sleep partners differ with respect to the specialist and the Home Care Provider, which stresses the importance of access to a variety of sources of information. Patients fitted with CPAP devices and who are globally satisfied with the treatment and level of care they receive have as yet unmet needs as regards the information and patient education received from their doctor.

This study obviously shows methodological weaknesses. First of all, there is nothing to guarantee that all of the questionnaires completed were filled out by patients and their sleep partners separately. Nevertheless, the high response rate shows that the role played by the family circle is an important issue for the Home Care Provider and the specialist with respect to disease management. It is also likely that the most dedicated sleep partners and the patients the most at ease with the treatment are those who responded. However it is clear, upon analysis of the responses, that their potential role can be improved.

5. CONCLUSION

SLEEP APNOEA SYNDROME and CPAP treatment have a notable impact on sleep partners. Even if the disease has a negative impact on the couple in general, the benefits of CPAP treatment are felt by both patients and their family circle; treating the patient often means treating the sleep partner at the same time. According to our observations, sleep partners not only play an essential role in detecting and diagnosing the disease but also influence CPAP use and continuation of treatment. The involvement of family members at the time of diagnosis and in disease monitoring appears to be essential. They have specific expectations which should be taken into account by doctors and Home Care providers. Providing additional information and therapeutic education is the key to effectively managing patients suffering from SLEEP APNOEA SYNDROME. Analyzing the reasons for

non-compliance with treatment/removal of fitted devices and the role played by the partner may also be very useful in practice and could form the subject of an additional study. Global disease management for patients should include their family and next of kin who have a strong influence on their psychological well-being, their way of dealing with the disease and their attitude to treatment. Finally, specialists' perception of the contribution made by the SLEEP APNOEA SYNDROME sufferer's family circle is also a route that remains to be explored.

SUPPORT/INTEREST

Orkyn' is a French Home care provider. It supplies CPAP for patients presenting with sleep apnea. "Association Passerelles éducatives" is a leading association in respiratory patient education.

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