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N.B.: When citing this work, cite the original article.

Original Publication:

Anders Broström, Anna Strömberg, Martin Ulander, Bengt Fridlund, Jan Martensson and Eva Svanborg, Perceived informational needs, side-effects and their consequences on adherence-A comparison between CPAP treated patients with OSAS and healthcare personnel, 2009, Patient Education and Counseling, (74), 2, 228-235.

http://dx.doi.org/10.1016/j.pec.2008.08.012

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http://www.elsevier.com/

Postprint available at: Linköping University Electronic Press http://urn.kb.se/resolve?urn=urn:nbn:se:liu:diva-17141

Perceived informational needs, side-effects and their consequences on adherence—A comparison between CPAP treated patients with OSAS and healthcare personnel

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Abstract

Objective

To compare perceptions among continuous positive airway pressure (CPAP) treated patients with obstructive sleep apnoea syndrome (OSAS) and healthcare personnel with regard to informational needs, side-effects and their consequences on adherence.

Methods

A cross-sectional descriptive design was used including 350 CPAP treated OSAS patients from three Swedish hospitals and 105 healthcare personnel from 26 Swedish hospitals. Data collection was performed using two questionnaires covering informational needs, side-effects and adherence to CPAP.

Results

Both groups perceived all surveyed informational areas as very important. Patients perceived the possibilities to learn as significantly greater in all areas (p < 0.001) compared to healthcare personnel, and scored significantly higher regarding positive effects on adherence of information about pathophysiology (p < 0.05), self-care (p < 0.001) and troubleshooting (p < 0.01). A total of 11 out of 15 surveyed side-effects were perceived to be more frequent by healthcare personnel (p < 0.01-p < 0.001). They also scored all side-effects to cause greater problems and decrease the CPAP use to a greater extent (p < 0.001).

Conclusion

Knowledge about these differences between patients and healthcare personnel regarding educational needs, side-effects and their effects on adherence can be important when designing educational programmes to increase CPAP adherence.

Practice implications

Measurement of these parameters before, during and after educational programs are suggested.

Keywords: Obstructive sleep apnoea syndrome; CPAP treatment; Education; Side-effects; Adherence

1. Introduction

Obstructive Sleep Apnea (OSA) is a condition consisting of repetitive episodic disturbances of breathing during sleep, due to a complete or partial obstruction of the upper airways [1]. The disturbed breathing might lead to fragmented sleep, in turn causing nocturnal [2] as well as daytime [3] symptoms. The prevalence of OSA is estimated to lie between 3% and 28%, the large variance explained by differences in diagnostic approaches and definitions of OSA [4] and [5]. The severity of the disorder is expressed as the number of total and/or partial events of respiratory obstruction per hour of sleep (AHI) and the number of oxygen desaturation events per hour of sleep (ODI). The combination of OSA and daytime symptoms is referred to as OSA syndrome (OSAS) [1]. Longstanding untreated OSAS may lead to detrimental health consequences [6], [7] and [8]. The treatment of choice is continuous positive airway pressure (CPAP). CPAP creates a continuous positive air pressure via a mask that opens up the upper airways, allowing the patient to breathe freely. CPAP treatment has been found to reduce several of the risk factors associated with OSAS and daytime symptoms, as well as to increase quality of life [9] and [10].

Defining adherence to CPAP can be difficult, since the necessary frequency of usage and number of hours of usage per night to attain and preserve a therapeutic effect is unknown [11]. A cut-off level of at least 4 h use per night has commonly been used [12]. To gain an optimal effect of the CPAP it is crucial to use it the whole time in bed [13]. Side-effects are common and cause high early dropout rates and low long-term adherence [14] and [15], why implementing interventions based on patient education are important [11] and [15]. Patient education can, from a general perspective, be defined as the process of improving knowledge and skills in order to influence the attitudes and behaviour required to maintain or improve health [16]. No generally accepted guideline for education of CPAP treated patients exists today neither from a topical or didactical aspect.

People tend to learn things that they perceive as important [17]. No studies have however, been performed where perceptions of educational needs among CPAP patients have been compared to the perceptions of healthcare personnel. Comparisons of patients and nurses have been done on patients with angina pectoris [18], myocardial infarction [19], congestive heart failure [20], cancer [21], and renal dialysis [22]. In general, the results indicated that all studied areas were perceived as important by patients as well as nurses. However, the ranking

of the relative importance of different areas often differed. Cancer nurses scored information about the purpose of chemotherapy to be of relatively low importance, while patients scored it to be the area of most importance. In the same study, nurses perceived patients' need for information about dealing with feelings as much more important than the patients did. In another study [20] patients and nurses were asked whether the learning goals were realistic. Patients tended to rate their learning abilities somewhat higher than nurses. However, perceptions of prevalence, magnitude and effect of side-effects on adherence have not, to our knowledge, been studied in healthcare personnel compared to patients in any diagnosis.

The aim of this study was therefore to compare perceptions among CPAP treated patients with OSAS and healthcare personnel with regard to informational needs, side-effects and their consequences on adherence.

2. Methods

2.1. Design and setting

This study used a cross-sectional descriptive survey design. In order to get a representative sample, patients were recruited from three different CPAP clinics (one university hospital, one provincial hospital and one private clinic) situated in one metropolitan city and two provincial cities in different parts of Sweden. Further, healthcare personnel were recruited from all 28 CPAP clinics in Swedish hospitals. The study protocol was approved by the Regional Ethics Committee for Human Research, Linköping University, Sweden.

2.2. Study populations

The patients (n = 453) were selected by applying the following criteria: age ≥ 18 years, diagnosis of OSAS (clinical symptoms and AHI ≥ 10) and CPAP treatment for ≥ 2 weeks. Exclusion criteria were: suffering from another life-threatening disease, a diagnosis of a serious psychiatric disease, dementia, communication problems or inability to read and speak Swedish. Inclusion criteria for healthcare personnel (n = 135) were that they should work primarily with CPAP treatment of OSAS and have ≥ 4 months of experience of this type of care.

2.3. Measurements

2.3.1. Demographical, clinical and adherence data

Demographic variables of both patients and healthcare personnel were collected via a postal questionnaire. Clinical variables of the patients (co-morbidities, blood pressure, body mass index, Epworth sleepiness scale (ESS), OSAS severity variables, self-rated sleep time) which routinely are collected at all visits were taken from the most recent visit in the medical records. Objective adherence to CPAP treatment was downloaded as minutes/night from the CPAP device. The CPAP use was dichotomised as machine usage above or below 4 h mean use/night (12), and machine usage above or below 85% of self-rated mean sleep.

2.3.2. Informational needs of CPAP treatment

Informational needs of CPAP-inventory (INC-I) [23] was developed by the research group for the study and used to measure perceptions about informational needs related to CPAP, as well as how healthcare personnel perceived the patients learning needs and capacity. INC-I includes six different themes; how sleep apnoea arises, how sleep apnoea affects sleep, how sleep apnoea affects health, how self-care activities can affect sleep apnoea, how the CPAP functions and should be used, and how problems related to the CPAP therapy can be solved. Each of the six themes includes three sub-questions answered on a five-point Likert type scale. The sub-questions focus on importance, possibility to understand and learn, as well as how knowledge about the actual theme improves CPAP use. An example of a theme revealed by sub-questions taken from the INC-I for both patients and healthcare personnel is presented in Table 1.

The other five included themes in the questionnaire are: how sleep apnoea affects sleep, how sleep apnoea affects health, how self-care activities can affect sleep apnoea, how the CPAP functions and should be used and how problems related to the CPAP therapy can be solved. When INC-I was answered by healthcare personnel the second and third sub-questions were reformulated, i.e., What are the possibilities for the patient to understand and learn information about this area? *and* How does information about this area improve the patients adherence to CPAP treatment?

Table 1: An example of a theme (How sleep apnoea arises) revealed by sub-questions taken from the informational needs of continuous positive airway pressure inventory (INC-I)

1. How sleep apnoea arises					
How important is information about this area?	not important	less than moderate importance 2	of moderate importance 3	more than moderate, less than very important 4	very important
What are the possibilities to understand and learn information about this area?	no possibilities	less than moderate possibilities 2	moderate possibilities 3	more than moderate, less than great possibilities 4	great possibilities 5
How does information about this area improve your use of CPAP?	no improvement	less than moderate improvement 2	moderate improvement 3	more than moderate, less than great improvement 4	great improvement 5

In the statistical processing and analysis of INC-I questions about importance of information, scores of 1–2 were considered to represent "not important", 3 "moderate" and scores 4 and 5 "very important". INC-I questions about the possibilities to understand and learn information 1–2 were considered to represent "no possibilities", 3 "moderate possibilities", 4 and 5 "great possibilities". INC-I questions about how the information improved the use 1–2 were considered to represent "no improvement", 3 "moderate improvement", and 4 and 5 "great improvement".

The content validity of both versions of INC-I was established with the themes extracted from in-depth interviews with OSAS patients before [24] and after CPAP initiation [25]. Face validity was checked by an expert panel with different backgrounds consisting of a sleep physician, an ear nose and throat physician, a pulmonary physician, four CPAP nurses and three nurses with extensive experience of instrument development. Content and face validity of the version for healthcare personnel were tested at a Swedish consensus congress for CPAP personnel with good results. A series of principal component analyses [26] was used to determine the dimensionality of the six themes in the INC-I. The analyses resulted in two logical dimensions (pathophysiology of OSA and CPAP treatment) that were consistent for all sub-questions and showed good internal consistency (Cronbach's alpha values of 0.76–0.84) supporting construct validity.

2.3.3. Side-effects of CPAP treatment

Side-effects of CPAP-inventory (SEC-I) [27] was developed by the research group and has been used in recent CPAP studies [28] to measure frequency, magnitude, and perceived impact of side-effects on adherence to CPAP treatment. SEC-I includes 15 different types of side-effects. Each side-effect includes three sub-questions answered on a five-point Likert type scale. The sub-questions focus on frequency, magnitude, as well as the decrease of CPAP use related to the actual side-effect. An example of a side-effect revealed by sub-questions taken from the SEC-I for both patients and healthcare personnel is presented in Table 2. The content and face validity of SEC-I was established for both patients and healthcare personnel using the same procedure as INC-I. A series of principal component analyses [26] was used to determine the dimensionality of the three scales in the SEC-I. The analyses resulted in two logical dimensions (device related side-effects and symptoms of OSA) for all sub-scales with good internal consistency (Cronbach's alpha values of 0.72–0.86) supporting construct validity. Convergent and discriminant validity tests showed that SEC-I could discriminate between people with different objective adherence to CPAP treatment (above or below 4 h CPAP use/night).

Table 2: An example of a side-effect (dry throat) revealed by sub-questions taken from the side-effects of CPAP-inventory (SEC-I)

1. Dry throat How frequently does this side-effect appear?	never	seldom 2	sometimes 3	often 4	very often 5
How great a problem does this side-effect cause?	no problems	small problems 2	some problems	great problems 4	very great problems 5
How does this side-effect decrease your use of CPAP?	not at all	a little	moderately	much 4	very much

The other 14 side-effects included in the questionnaire are: blocked up nose, runny nose, nose bleed, irritated eyes, irritated bowel, transient deafness, feeling uncomfortable because of wearing CPAP in front of others, increased awakenings, uncomfortable pressure of the mask, mask leaks, cold air, disturbing noise, problems to exhale and anxiety during treatment. When SEC-I was answered by healthcare personnel the second and third sub-questions were reformulated, i.e., How great a problem does this side-effect cause for the patient? *and* How does this side-effect decrease your use of CPAP for the patient?

In the statistical processing and analysis of SEC-I questions about frequency of side-effects, scores of 1–2 were considered to represent "never", 3 "occasionally", and scores 4 and 5 "habitually". SEC-I questions regarding magnitude of side-effects 1–2 were considered to represent "no complaints", 3 "moderate complaints", and scores 4 and 5 "major complaints". SEC-I questions regarding decrease of CPAP use related to side-effects scores 1–2 were considered to represent "no decrease", 3 "moderate decrease", and scores 4 and 5 "major decrease".

2.4. Data collection

Eligible patients were found through a screening process of the patient registries at three different CPAP clinics made by the first author (AB). An informative letter about the study, a questionnaire collecting demographic data, INC-I and SEC-I was administered to 453 patients with OSAS fulfilling the inclusion criteria. A total of 135 eligible healthcare personnel (MD, RN, PT and BMA) at all Swedish hospitals known to be working with CPAP also received an informative letter, a questionnaire collecting demographic data, INC-I and SEC-I. One mailed reminder was sent to both patients and healthcare personnel. The inclusion process was performed from November 2006 to September 2007.

2.5. Statistical processing and analysis

Descriptive statistics were used to describe the study population. Categorical demographic variables were analysed with the Chi-square test. Normally distributed continuous variables (clinical and adherence data) were analysed with the Student's *t*-test (two-tailed) and are presented as means and standard deviations (S.D.). The statistical processing of INC-I questions about importance of information, the possibilities to understand and learn, and how the information improved the use of CPAP is presented in the heading for Table 1. The

statistical processing of SEC-I questions about frequency and magnitude of side-effects and decrease of CPAP use are presented in the heading for Table 2. Since data were on an ordinal level and not normally distributed Mann–Whitney U test was used to perform significance tests of the median scores of the variables from the INC-I and SEC-I between CPAP treated OSAS patients and healthcare personnel. Sub-group analyses were performed related to gender, educational level, marital status, and time after CPAP initiation among patients, and gender, profession and experience of CPAP care among the healthcare personnel. A two-tailed p < 0.05 was considered significant.

3. Results

3.1. Sample description

A total of 350 patients (65% men) out of 453 eligible patients (77%) answered the questionnaires. The 103 non-respondents did not differ regarding age or time after CPAP initiation. The majority of the respondents were married and had 12 or more years of education. A total of 86% of the patients used CPAP devices with fixed pressure, and 18% had a humidifier. The mean time after CPAP initiation was 55.9 months (2 weeks–182 months), and the mean time since last visit 6.5 months (2 weeks–16 months). A total of 105 out of 135 eligible healthcare personnel (78%) from 26 out of 28 eligible hospitals (93%) answered the questionnaire. Demographic data of the patients with OSAS and the healthcare personnel are summarised in Table 3.

Table 3: Demographical and clinical data in CPAP treated patients with obstructive sleep apnoea syndrome (OSAS) and healthcare personnel

Patients with OSAS, n = 350		Healthcare personnel, <i>n</i> = 105		
Gender: n (%)		Gender: n (%)		
Men	230 (65)	Men	20 (19)	
Women	120 (35)	Women	85 (81)	
Age mean (S.D.) 59.5 years Age mean (S.D.) 45.0 years (9.15)				

Patients with OSAS, $n = 350$	Healthcare personnel, <i>n</i> = 105		
Educational level: n (%)	Profession: n (%)		
Compulsory education (6 years)	94 (27)	RN	41 (39)
Further education (9 years)	74 (21)	MD	25 (24)
Higher education (12 years)	106 (30)	BMA	23 (22)
University (15 years or more)	76 (22)	PT	16 (15)
Marital status: n (%)		Experience of C	PAP care: n (%)
Married	249 (71)	4–12 months	11 (10)
Unmarried	62 (18)	13–24 months	12 (11)
Divorced	28 (8)	25–48 months	20 (19)
Widow/widower	11 (3)	>48 months	62 (59)
Self-reported comorbidity: <i>n</i> (%)			
Hypertension	161 (46)		
Angina pectoris	42 (12)		
Acute myocardial infarction	21 (6)		
Stroke	8 (2)		
Diabetes 74 (21)			
BMI: mean (range):	32.8 (21–49)		
OSAS variables: mean (range)			
AHI before CPAP: 45.9 (10–98)			
ODI before CPAP: 41.5 (10–90)			
Excessive daytime sleepiness: mean (S.D.)			
ESS before CPAP:	12.2(4.8)		
ESS with CPAP:	7.4(4.9)		
Time (months) after CPAP initiation: mean (range)	55.9(0–182)		

Patients with OSAS, $n = 350$	Healthcare personnel, <i>n</i> = 105	
CPAP pressure: mean (S.D.) 9.6(2.6)		
Time (months) since last visit: mean (range)		
CPAP adherence		
Minutes/night: mean (S.D.)	342.2(92.8)	
≥4 h mean use/night (%)	79	
Above 85% of self-rated sleep time (%) 68		

AHI, Apnea-hypopnea index measured during sleep; BMA, biomedical analyst; BMI, body mass index; CPAP, continuous positive airway pressure; ESS, Epworth sleepiness scale; MD, physician; ODI, oxygen desaturation index measured during sleep; RN, registered nurse.

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3.2. Perceived educational needs related to OSAS and CPAP among patients compared to healthcare personnel

Both CPAP treated patients and healthcare personnel perceived information about almost all themes in the INC-I as very important (Table 4). Healthcare personnel scored significantly higher regarding the importance of information about how sleep apnoea arises (p < 0.01), how sleep apnoea affects sleep (p < 0.001) and how the CPAP functions and should be used (p < 0.01). No differences were found between healthcare personnel with different professions or experience of CPAP care. The patients scored information about how sleep apnoea affects sleep to be a theme of less importance, while healthcare personnel scored all of the themes to be of great importance. Patients scored significantly higher regarding the possibilities to learn about all six themes of the INC-I compared to healthcare personnel (p < 0.001). More than 50% of the healthcare personnel scored patients to have no or moderate possibilities to learn about how sleep apnoea arises, self-care effects on sleep apnoea and troubleshooting of the CPAP.

Table 4: Data from the informational needs of continuous positive airway pressure inventory (INC-I) describing (%) the perceived learning needs of CPAP treated patients with obstructive sleep apnoea syndrome (OSAS) in relation to healthcare personnel working primarily with CPAP treatment

-	n=105
86**	95
84***	47
72*	50
29***	92
90***	62
77	82
95	99
90***	51
77	81
apnoea	
92	92
85***	33
73***	37
	84*** 72* 29*** 90*** 77 95 90*** 77 apnoea 92 85***

Variables from INC-I	Patients with OSAS n = 350	Healthcare personnel n = 105		
How important (very important)	91**	99		
What are the possibilities to learn (great possibilities)	94***	65		
How it improves the use (major improvement)	81*	74		
6. How problems related to the CPAP therapy can be solved				
How important (very important)	94	94		
What are the possibilities to learn (great possibilities)	83***	37		
How it improves the use (major improvement)	80**	68		

*p < 0.05, **p < 0.01, ***p < 0.001. Mann–Whitney U test is used to perform significance tests of the median scores of the variables from the INC-I between CPAP treated OSAS patients and healthcare personnel.

3.3. Perceived side-effects to CPAP among patients compared to healthcare personnel

Healthcare personnel scored significantly higher (p < 0.05–p < 0.001) regarding frequency of 11 out of the 15 side-effects listed in the SEC-I compared to CPAP treated patients with OSAS. The five most common side-effects as perceived by healthcare personnel were; blocked up nose, mask leaks, dry throat, uncomfortable pressure of the mask and runny nose. The five most common side-effects among patients were; dry throat, uncomfortable pressure of the mask, feeling uncomfortable because of wearing CPAP in front of others, blocked up nose, and mask leaks. On the other hand, the five most uncommon side-effects among patients were; nosebleed, anxiety during treatment, transient deafness, problems to exhale, and cold air. Healthcare personnel scored transient deafness, nose bleed, irritated bowl, anxiety during treatment and irritated eyes as the five most uncommon side-effects. Regarding the perceived magnitude of the problem, healthcare personnel scored significantly higher (p < 0.001) in all of the 15 side-effects compared to OSAS patients. A blocked up nose and dry throat were perceived as a "major problem" by 52% and 46% of the healthcare personnel, while 11% and 16% of the patients perceived these side-effects as a "major

problem" (Table 5). The four side-effects scored to cause the greatest problems among patients were: dry throat, blocked up nose, mask leaks and uncomfortable pressure from the mask. No significant differences regarding frequency and severity of the 15 side-effects listed in the SEC-I were found between healthcare personnel with different professions or experience of CPAP care.

Table 5: Data from the side-effects of CPAP-inventory (SEC-I) describing the self-rated prevalence (%) of frequency and magnitude of selected side-effects, as well as the decreased use of CPAP treatment in CPAP treated patients with obstructive sleep apnoea syndrome (OSAS) in relation to healthcare personnel working primarily with CPAP treatment

Variables from SEC-I	Patients with OSAS n = 350	Healthcare personnel n = 105
1. Blocked up nose		
How frequent (occasionally/almost always)	29/20***	39/52
How great problem (moderate/major)	33/11***	48/52
Decrease of use (moderate/major)	22/12***	30/66
2. Dry throat		
How frequent (occasionally/almost always)	30/33***	41/44
How great problem (moderate/major)	30/16***	49/46
Decrease of use (moderate/major)	22/8***	49/47
3. Feeling uncomfortable because of we	aring CPAP in front of other	rs
How frequent (occasionally/almost always)	14/20	28/8
How great problem (moderate/major)	7/4***	27/14
Decrease of use (moderate/major)	3/3***	21/21
4. Increased awakenings		
How frequent (occasionally/almost always)	29/15***	50/8
How great problem (moderate/major)	26/7***	44/24
Decrease of use (moderate/major)	18/6***	35/35

Variables from SEC-I	Patients with OSAS n = 350	Healthcare personnel n = 105		
5. Uncomfortable pressure from the mas	sk	1		
How frequent (occasionally/almost always)	37/33***	64/24		
How great problem (moderate/major)	29/11***	54/35		
Decrease of use (moderate/major)	17/7***	50/41		
6. Mask leaks				
How frequent (occasionally/almost always)	42/17***	53/45		
How great problem (moderate/major)	32/10***	48/48		
Decrease of use (moderate/major)	20/9***	41/54		
7. Problems to exhale				
How frequent (occasionally/almost always)	12/4***	47/5		
How great problem (moderate/major)	12/5***	41/30		
Decrease of use (moderate/major)	10/3***	41/31		
8. Anxiety during treatment				
How frequent (occasionally/almost always)	8/4***	31/1		
How great problem (moderate/major)	7/3***	35/17		
Decrease of use (moderate/major)	5/4***	37/22		

^{***}p < 0.001. Mann–Whitney U test is used to perform significance tests of the median scores of the variables from the SEC-I between CPAP treated OSAS patients and healthcare personnel.

3.4. Perceived consequences of educational needs and side-effects on adherence among patients compared to healthcare personnel

Both patients and healthcare personnel perceived information regarding most of the themes in the INC-I to have a major positive impact on CPAP use (Table 4). Patients scored significantly higher for the positive effect on adherence of information about how sleep apnoea arises (p < 0.05), how self-care activities can affect sleep apnoea (p < 0.01), how the CPAP functions and should be used (p < 0.01), as well as how problems related to CPAP can be solved (p < 0.01). Over 50% of the healthcare personnel perceived information about how sleep apnoea arises and how self-care activities can affect sleep apnoea to have no or moderate improvement on CPAP use. Healthcare personnel perceived all side-effects to decrease the use of CPAP to a greater extent as compared to OSAS patients (p < 0.001). A blocked up nose, mask leaks, dry throat and uncomfortable pressure from the mask (i.e., the four side-effects scored to cause the greatest problems) were scored to have a major negative effect on use by 66%, 54%, 47% and 41% of the healthcare personnel, while 12%, 9%, 8% and 7% of the patients scored these side-effects to have a major negative effect on use.

Sub-group analyses were performed for all areas in INC-I and SEC-I. In the patient group there were no differences related to gender, educational level, marital status, time after CPAP initiation. Further, there were no differences with regard to gender, profession and experience of CPAP care among the healthcare personnel.

4. Discussion and conclusion

4.1. Discussion

No generally accepted guidelines for education to patients before and during CPAP initiation exist today [29]. This is a limitation, since education about OSAS, CPAP and self-care activities might be factors of importance in order to increase adherence in the use of CPAP. Patients have described the need for adequate information before, during, as well as after initiation of CPAP treatment [24]. If adequate education is not given, it can cause fear, anxiety and non-adherence [25]. This raises the question about what informational areas are of importance and we therefore in this study compared perceptions among patients and healthcare personnel with regard to informational needs, side-effects and their consequences on adherence.

Our findings showed that both CPAP treated patients and healthcare personnel perceived most informational areas as important, but patients scored significantly higher regarding the perceived possibilities to learn and the positive effects of information on adherence.

Healthcare personnel scored significantly higher regarding the importance of information about how sleep apnoea arises, how sleep apnoea affects sleep, how the CPAP function and should be used, and how problems related to the device can be solved. Healthcare personnel scored significantly higher regarding frequency, magnitude and negative effect of most side-effects compared to patients. With these differences in mind healthcare personnel should involve the patient in the process when informational needs are assessed, as well as when educational materials and programmes are developed.

Despite the poor adherence to CPAP treatment, intervention studies based on patient education are few. They have used different didactical approaches not clearly based on perceived learning needs of the patients and have shown conflicting results [30], [31], [32], [33], [34], [35], [36] and [37]. Group education seems promising [30], [33], [35] and [36]. Group education for 2 h every 6 months improved CPAP use significantly [30], and a multidisciplinary programme based on group education with six workshops related to OSAS, different aspects of CPAP treatment, as well as suitable self-care activities improved excessive daytime sleepiness [35]. Another study using verbal education in small groups improved knowledge about sleep apnoea [33]. Video education showed limited effects on knowledge [32] and adherence [31], even when written information about OSAS and CPAP, as well as telephone support was added [31]. On the other hand, a 15 min educational video during the initial visit improved the return rate to a CPAP clinic after 1 month [34]. An intervention based on two sessions with cognitive behavioural therapy including educational video increased adherence to CPAP treatment [36]. An extensive home-based individual education on four occasions during 3 months did not significantly improve adherence when compared to standard education with verbal information about OSA and the CPAP device [37]. The reason for the conflicting results in these studies might be small sample sizes, lack of power in the educational intervention, or lack of validated and reliable instruments. Besides which, enough attention may not have been paid to the didactical process and the perceived learning needs of patients to improve the adherence to CPAP treatment.

Patients in our study scored high on the positive effects of education on adherence. However, increased knowledge does not automatically lead to increased adherence [38]. Our findings

show that the relationship between what is perceived as important information, and what information that is perceived to have a positive effect on adherence among healthcare personnel is complex and somewhat difficult to explain. Patients perceived the possibilities to learn and the positive effects of education on CPAP use to be higher than healthcare personnel. An explanation for the difference between patients and healthcare personnel might be that patients are not fully aware of all pathophysiological consequences that can have a negative effect on memory and cognitive functions [3]. Other explanations can be that healthcare personnel scored the patients possibilities to learn from the former situation as a sleepy OSAS patient, not as a less sleepy CPAP user. The perception of sufficient knowledge might also be higher for healthcare personnel compared to the patients.

Other factors of importance in the educational situation, not included in the above-mentioned studies [30], [31], [32], [33], [34], [35], [36] and [37], or measured in our study, can be behavioural aspects, such as motivation, self-determination and the process of creating a habit of using the CPAP treatment. Drieschner et al. [39] described motivation to engage in treatment as dependent on six cognitive and emotional internal determinants: problem recognition, level of suffering, external pressure, perceived cost of treatment, perceived suitability of treatment, outcome expectancy, motivation to engage in treatment, and treatment engagement.

Side-effects are common among CPAP users especially during the initiation process, but also later when patients are custom users [9], [11], [15] and [29]. An important finding in our study was that healthcare personnel scored significantly higher regarding frequency, magnitude and impact of most of the side-effects in the SEC-I as compared to patients. These differences may be of importance, since healthcare personnel might emphasize side-effects differently in the educational situation causing misconceptions [40]. The use of a questionnaire, such as SEC-I could therefore be important to explore the patient perspective regarding frequency, magnitude and impact of side-effects. However, healthcare personnel and patients agreed regarding four of the five most common side-effects (blocked up nose, mask leaks, dry throat, uncomfortable pressure of the mask). This is in line with older [10], [41] and [42], as well as recent studies [43] and [44].

Type D (distressed) personality (i.e., a combination of negative affectivity and social inhibition) can significantly increase the perception of a broad range of side-effects from CPAP treatment [28]. Those patients experienced the side-effects as more troublesome and

rated the subjective adherence lower than patients without Type D personality. Adaptation to and acceptance of side-effects can appear after the initial period, especially if the patient gets a positive effect of the CPAP treatment [25] and [45].

4.2. Limitations

This study used a cross-sectional design. Measuring perceptions of informational needs and side-effects among patients and healthcare personnel on one specific occasion might lead to some limitations since side-effects might change over time. There is therefore a need for prospective studies following these parameters from the initiation of CPAP and during long-term use. Our study did include CPAP users in the early stages of treatment and those that interrupted treatment before 6 months. This might explain the differences in the profile of the side-effects reported in other studies [10], [36], [37], [41] and [42]. Some side-effects might have a greater frequency and magnitude initially. Healthcare personnel answered INC-I and SEC-I from a general perspective. One might think that recent experiences of patients reporting several side-effects and low adherence might affect the responses. A matched sample of patients and their own healthcare personnel would have provided a more robust sample. However, this can be seen as difficult from a practical, as well as clinical perspective, especially with a large sample size. INC-I and SEC-I are two newly developed promising instruments and psychometric testing regarding validity and reliability are in progress.

4.3. Conclusion

This is the first study comparing perceptions among CPAP treated patients with OSAS and healthcare personnel with regard to informational needs, side-effects and their consequences on adherence. CPAP treated OSAS patients, as well as healthcare personnel perceived most informational areas as important, but patients scored significantly higher regarding the perceived possibilities to learn and the positive effects of information on adherence. Healthcare personnel scored significantly higher regarding frequency of the majority of the side-effects compared to patients, but both groups agreed regarding what side-effects were the most common ones. Knowledge about these differences can be important when designing educational programmes to increase CPAP adherence.

4.4. Practice implications

Healthcare personnel who provide education should initially focus on exploring and formulating individual learning needs, e.g. through INC-I, and identifying human material resources and educational barriers related both to the disease, as well as to the psychosocial situation (lack of support resources). Psychosocial aspects such as the patients' experiences related to the level of suffering (physical and social stressors expressed as disability or burden), as well as different types of external pressure (comorbidities and social situation) that later in the process might affect adherence negatively, should be discussed.

Knowledge about possible barriers for learning in OSAS patients should be considered in the educational situation. Long-term sleep deprivation is known to affect mood, cause depressive symptoms and cognitive dysfunction. These symptoms can affect the possibilities to learn. The didactical approach (i.e., choosing and implementing appropriate learning strategies) is therefore of great importance. Using small groups, including the partner, with different approaches (i.e., practical, verbal, written and video) may be preferable to increase possibilities to learn. Behavioural theories could be used to strengthen self-determination and treatment motivation to facilitate the development of a habit.

Education about symptoms, the pathophysiological process, side-effects and device troubleshooting should be emphasized. Both INC-I and SEC-I could be used continually to measure informational needs and side-effects to decrease early dropouts and facilitate coping. Education concerning positive effects of the forthcoming treatment should be emphasized since it might strengthen self-determination. In a wider context this can be seen as informed choices about how the CPAP treatment should be used and possible side-effects handled. The later parts of the programme could focus on the understanding of the cause and effect of risk factors (e.g. obesity and hypertension), as well as the importance of dietary changes and weight loss to reduce the risk for concomitant diseases, which may occur despite treatment for OSAS. Conquering these types of behavioural changes might be easier if daytime symptoms have decreased and the CPAP has become a habit. Realistic goals for the education that stimulates the patient to actively participate in their own care should be formulated (i.e., evaluating learning outcomes) in all stages of the educational situation.

Acknowledgements

The authors wish to thank the Health Research Council in the South-East of Sweden for financial support, Grant FORSS-8964. We wish to thank Gerd Pihl and Maria Högquist from the Department of Clinical Neurophysiology, Linköping University Hospital, as well as Jan Albers and Anna Ståhlkrantz from the Department of Internal Medicine, County Hospital Ryhov, Jönköping, Sweden, for their contributions to the study.

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