Shared decision making: A novel approach to personalized treatment in obstructive sleep apnea☆

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ABSTRACT

Study objectives: i) To describe a novel approach of phenotyping by shared decision making (SDM) in obstructive sleep apnea (OSA) discharge consultations ii) to describe correlation between patient and observer based evaluations of SDM and iii) to describe treatment adherence.
Methods: Consecutive patients referred to the otorhinolaryngology department at Akershus University Hospital with suspected OSA between 2015 and 2016 participated. Patients with body mass index >30 were oversampled. Four male communication-trained doctors aged from 30 to 60 years participated. SDM was evaluated by modified content analysis and by the CollaboRATE self-report questionnaire and the "Observer OPTION (Young et al., 2008) [5]" rating scale. Positive airway pressure (PAP) treatment adherence and weight reduction was assessed by interview at six year follow-up.
Results: Eighteen consultations were video filmed. The content analysis revealed that the patient perspectives only briefly were explored. PAP was chosen by 17 of 18 patients. Median CollaboRATE questionnaire score was 29 (26, 30). Mean OPTION (Young et al., 2008) [5] score was 65.6 (SD 6.6, range 55 −80). The correlation between SDM assessed by CollaboRATE self-report and by the "Observer OPTION (Young et al., 2008) [5]" rating scale was low (Pearson's r = 0.09). At follow up, 11 patients (64.7%) were PAP adherent and no one achieved 10% weight loss.
Conclusions: Despite a high degree of SDM compared to studies of non-OSA populations, the sub-optimal exploration of the patient perspective by communication-trained doctors precluded identification of patients willing to cope actively. SDM assessed by self-report and by a rating scale may represent two different constructs. PAP adherence was good.

1. Introduction

Obstructive sleep apnea (OSA) is a common disorder. A Norwegian study has estimated the prevalence of OSA defined by an apnea hypopnea index (AHI) of $\geq$ 15 events/hour, to be 8 % among adults aged 30−65 [1]. Other studies have found higher prevalence estimates of moderate to severe OSA, up to 50% in men and 25% in women in a middle-aged general population [2,3]. Untreated OSA is associated with increased risk of mortality and morbidity [4,5]. OSA is recognized as a secondary cause of hypertension [6] and is associated with increased risk of cardiovascular disease [7,8], cognitive impairment [9] and symptoms of depression [10]. Recent research has advocated the use of phenotyping when choosing appropriate treatment for patients with OSA [11]. However, the concept of phenotyping is multifaceted across the literature.

Treatment with positive airway pressure (PAP) is the standard intervention for patients with moderate to severe OSA. It has been

shown to relieve sleepiness symptoms, to be cost-effective in patients with moderate to severe OSA [12,13] and may reduce cardiovascular risk [14]. PAP in combination with lifestyle interventions is the most effective therapy for patients with moderate to severe OSA [15]. Non-adherence to treatment with PAP or weight loss is a major clinical challenge among patients with OSA [12,16,17]. Approximately 25%–83% of patients with OSA are non-adherent to PAP depending on age group, country, assessment methods and the various cut-off criteria for adherence being used [17,18]. Weight loss is recommended to all overweight or obese patients with OSA, including those using PAP [19]. However, lifestyle interventions alone are in most patients not sufficient to achieve and maintain weight loss. Regarding non-surgical weight loss, motivation is probably a crucial factor [16].

Shared decision making (SDM), as opposed to clinicians making decisions on behalf of patients, has become an ideal in contemporary clinical practice. SDM can identify patients' motivation for active coping [20], but there is no standardized way to clarify what actually happens in practice [21]. SDM has been defined as "an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences" [22]. Doctors and patients bring different but equally important forms of expertise to the decision to be made. Based on this background, we hypothesized that a descriptive study of phenotyping by SDM may identify patients willing to actively cope with OSA.

There is a lack of studies describing SDM in clinical sleep medicine populations. However, a recently published randomized controlled trial suggests that a multifaceted, patient-centered intervention, based on SDM and with caregiver involvement can improve PAP adherence in adult patients with OSA [23].

The aims of this study are: i) to describe a novel approach of phenotyping by SDM in OSA discharge consultations ii) to describe correlation between patient and observer based evaluations of SDM and iii) to describe treatment adherence.

2. Methods

2.1. Study population

The Akershus Sleep Apnea (ASAP) Clinical Cohort consists of 275 consecutive individuals referred to the otorhinolaryngology department at Akershus University Hospital with suspected OSA. Patients underwent sleep registration and clinical examination between August 2015 and September 2016. The inclusion criteria were similar to those of the European Sleep Apnea Database (ESADA) [24]. Patients with suspected OSA (male or female, aged 18–80 years) were screened as eligible for inclusion and included if they were able to speak, read and understand the Norwegian language, possessed the ability to respond to questions and follow instructions and signed informed consent. Exclusion criteria were previously diagnosed or treated sleep apnea, a limited life expectancy due to illness unrelated to sleep apnea (e.g. HIV, advanced renal disease, uncontrolled malignancies) or alcohol or drug abuse up to 1 year prior to inclusion in the study as assessed by interview. In addition, patients with body mass index (BMI) < 30 kg/m^2 were excluded from this sub study to increase the likelihood of needing treatment.

Of 275 participants, 165 were diagnosed with OSA. Among these, 75 were not eligible for participation according to the BMI criterion. During the discharge consultation, patients with newly diagnosed OSA could by protocol choose no treatment, primary surgery if indication (Friedman classification 1 or 2) [25], self-managed 10% weight reduction and/or treatment with PAP.

Patients diagnosed with OSA (respiratory event index, REI, $\geq$ 5 plus symptoms) and BMI >30 were asked to participate in this sub study involving video recording of consultation. Eighteen of 89 patients with these inclusion criteria consented to be video filmed during the discharge consultation (Fig. 1). Four out of 14 doctors consented to video filming. All four were men aged from 30 to 60 years.

2.2. OSA diagnostic assessment

Sleep was assessed by either in-hospital polysomnography (PSG) (Nox A1, Nox Medical, www.noxmedical.com) (N = 14), a catheter based polygraph (Apneagraph 200 or Apneagraph Spiro (N = 1), Spiro medical (www.spiromedical.com) or a standard polygraph (Nox T3, Nox Medical, www.noxmedical.com) (N = 3). Sleep and respiratory events were scored according to the 2012b American Academy of Sleep Medicine (AASM) criteria [26]. The 2012b criteria, with a 4% oxygen desaturation threshold, was chosen because data simultaneously was collected for a diagnostic study [27]. Hypopneas were scored if airflow dropped below 70% for more than 10 s with an oxygen desaturation of $\geq$ 4 %.

Due to partly use of polygraph scoring in the sample, the severity of OSA was evaluated by the respiratory event index (REI) according to the current version of the sleep scoring manual [28]. REI was calculated as the number of apneas and hypopneas per hour of recording according to the recommendations of the AASM [26]. The participants were categorized according to standardized criteria as having no OSA (REI<5), mild OSA (REI $\geq$5 to<15, plus symptoms), moderate OSA (REI $\geq$15 to <30) or severe OSA (REI $\geq$30) [28]. A minimum of 4 h of continuous registration with acceptable signal quality on key variables (pressure cannula, flow cannula and oximeter) was defined as minimum quality.

2.3. Clinical measures

All participants completed a comprehensive baseline assessment consisting of validated questionnaires and otorhinolaryngology clinical status. Weight, BMI and blood pressure were measured.

2.4. Communication training of relevance to SDM

Before study start, otolaryngologist specialists or supervised specialist candidates were encouraged to perform a 16 h communication course which was a condensed version of "The Four Habits", previously shown to significantly improve communication skills [29]. Exploring the patient perspective and SDM are
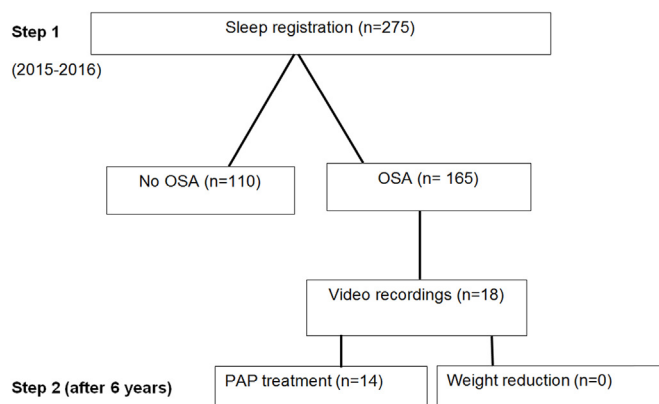

Fig. 1. Flow chart of the study.

important topics in the course curriculum [30].

2.5. Measures of SDM

2.5.1. Content analysis

Content analysis is a prominent, qualitative method used for the analysis of message content [31]. We have used this method to explore the patients' presuppositions, the unraveling of the patient perspectives and the doctors' responses. After identifying key content of interests based on the study goal (assumptions, patients' values, preferences, social conditions and attitude to risk), we have identified all the moments where the doctors and patients expressed relevant content related to the study goal, and inductively derived some categories to condense the meanings that emerged from the analysis. We have then reported the frequencies for these categories.

2.5.2. CollaboRATE questionnaire

The CollaboRATE questionnaire is a three item patient-reported measure for SDM with acceptable content validity [32]. The questionnaire measures the three core dimensions of SDM including: 1) information provision by clinician to patient; 2) patient preference elicitation; and 3) patient preference integration [32]. The CollaboRATE included these items: 1) How much effort did this doctor make to help you understand your health issues?; 2) How much effort did this doctor make to listen to the things that matter most to you about your health issues?; and 3) How much effort did this doctor make to include what matters most to you in choosing what to do next? CollaboRATE responses for each item was rated on a scale from 0, "no effort was made" to 10, "every effort was made". Maximum total score is 30.

2.5.3. Observer OPTION [5]

The "Observer OPTION [5]" scale measures SDM by focusing on the core aspects by assessing recordings or transcripts of encounters from clinical settings [33]. The "Observer OPTION [5]" describes doctors' degree of SDM through the three talk model of SDM based on "team talk," "option talk" and "decision talk [34]. Team talk is about working together, describing the options and providing support to patients when they are made aware of choices, and asking about goals to guide decision making processes. Option talk focuses on the task of discussing alternatives using the principles of risk communication. Decision talk refers to the task of coming to decisions that reflect the patient's informed preferences, led by knowledge and experience from healthcare professionals [34].

We used the "Observer OPTION [5] Manual" to measure SDM by assessing recordings of encounters from discharge consultations [35]. The OPTION [5] measurement was based on five items scored from 0, "no effort/zero effort observed", to 4, "exemplary effort/ clear, accurate communication methods used", with the maximum score of 20^{33}. We rescaled this sum score to be between 0 and 100 in accordance with the manual. The measurement included: Item 1) Does the clinician present multiple options?; Item 2) Does the clinician establish a partnership with the patient?; Item 3) Are the options described?; Item 4) Does the clinician ask the patient for their preferences?; and Item 5) Are the patients' preferences included in the decision about next steps? [35]. Two raters independently assessed each specific, timed decision focus in the clinical encounter. Both raters were medical doctors; one of them was a specialist in psychiatry. Both raters completed the «Observer OPTION [5] training » via Google classroom prior to study start.

2.5.4. Adherence

A telephone consultation was conducted six years after baseline. Self-reported PAP adherence was examined through an interview, based on three multiple choice questions about average PAP use: 1) Do you use PAP for your sleep apnea? (Response alternatives: Yes, no, or do not know), 2) How many nights/week do you use PAP? (Response alternatives: 1−7 nights/week), 3) How much of the sleeping time each night do you use PAP? (Response alternatives: All the sleeping time (100%), almost all the sleeping time (80−90%), most of the sleeping time (60−79%), about half of the sleeping time (40−59%), about one third of the sleeping time (20−39%), almost none of the sleeping time (1−19%), none of the sleeping time (0%), do not know) [36]. Individuals reporting PAP use for ≥5 days per week and ≥4 h per night on average for the past 4 weeks were classified as adherent and patients not meeting these criteria were classified as partial adherent [36,37]. Non-adherent patients were reporting nonuse and had given up their machines. Significant weight loss was defined as 10% reduction of baseline weight. Weight at follow-up was self-reported. For three patients lost to follow-up, adherence was examined by journal notes.

2.6. Statistics

Recordings were analyzed independently by two observers using "Observer OPTION [5]". Intraclass Correlation Coefficient (ICC) was calculated for groups of five videos until ICC>0.6. The two independent raters went through a three-score process of the first five videos in order to obtain satisfactory agreement because ICC was below threshold (under 0.6). We took detailed notes of conversations and examples of language used to differentiate between a score of 1 versus 2 and so on [35]. The results were discussed between the two raters for calibration and consensus. The next five video recordings were a two-score process. The last eight video recordings were performed in two processes with satisfactory ICC on the first attempts.

Descriptive statistics were reported as absolute numbers with percentages and standard deviations (SD) or medians with quartile one (Q1) to quartile three (Q3). Categorical variables between video filmed patients and patients not video filmed were compared with the Pearson's Chi Squared test and continuous variables were tested with the Mann−Whitney U test. Threshold of statistical significance was $p < 0.05$. The statistical analyses were performed using StataSE 16.1 (College Station, TX: StataCorp LLC).

2.7. Ethical approvals

The study was performed according to the Declaration of Helsinki, approved by the Regional Committee for Medical Research Ethics in eastern Norway, ID 2013/2294. All participants provided written informed consent prior to the study commencement.

3. Results

Characteristics of the study sample are presented in Table 1. Ninety patients with OSA met the inclusion criteria of being video filmed. In these patients, 18 (20%) discharge consultations were filmed. The 18 video filmed patients differed significantly in the BMI from the 147 OSA patients in the cohort not being filmed. There were no other significant differences between participants and non-participants with OSA. Four doctors out of 14 working at the sleep department accepted to participate. They were video filmed in 11 (61%), 3 (17%), 2 (11%) and 2 (11%) of the consultations respectively.

The results of the content analysis and follow up consultations are presented in Table 2. Most patients (14 of 18 patients) were negative or neutral to treatment with PAP in the initial phases of the consultations. Patients who were categorized as symptomatic and patients that knew other PAP users were most positive in their

Table 1
Characteristics of the video filmed patients.

Variable	OSA video filmed
N (%)	18 (11.0)
Age, mean (SD)	47.8 (9.3)
Female sex, n (%)	4 (22.2)
BMI, kg/m^2, mean (SD)	35.7 (3.8)
Systolic blood pressure, mean (SD)	148.5 (19.3)
Diastolic blood pressure, mean (SD)	83.2 (10.0)
REI, median (Q1, Q3)	25.7 (12.0, 44.1)
ODI, median (Q1, Q3)	23.9 (14.5, 44.1)
SpO2, %, median (Q1,Q3)	91.7 (90.8, 93.5)
% of total sleep time with SpO2 < 90%, median (Q1, Q3)	10.3 (3.8, 28.4)
SpO2 nadir, %, median (Q1, Q3)	83.0 (79.0, 84.9)
CollaboRATE questionnaire score, median (Q1, Q3)	29.0 (26.0, 30.0)
"Observer OPTION5" score, mean (SD)	65.6 (6.6)

BMI: Body Mass Index. REI: Respiratory event index. ODI: Oxygen Desaturation Index. SpO2 nadir: Lowest oxygen saturation.

presupposition (Table 2, column 1). The content analysis also revealed only briefly exploration of the patient perspectives, like patients' values, preferences, social conditions and attitude to risk (**column 2**). Moreover, doctors to a little degree responded to patient perspectives (Table 2, column 3). One of the doctors' expressed: "*It is my challenge to try to convince* you". The treatment decision was treatment with PAP in 17 of 18 patients. Weight reduction was discussed in all the consultations. Fourteen patients decided to reduce weight by 10%, but doctors to a little degree explored how the patient could achieve this. No referrals to weight reduction regimen were done. One patient was scheduled for nasal septoplasty combined with lifestyle advice and a follow-up consultation (Table 2, column 4). After six years, three of four (75.0%) patients with positive presupposition were PAP adherent, six of nine (66.7%) patients with neutral presupposition were adherent (two were lost to follow-up) and of these four patients with negative presupposition, two patients (50.0%) were adherent. Two patients (22.2%) with neutral presupposition were partial adherent (one was lost to follow-up) and one patient (25.0%) with negative presupposition was partial adherent. Three patients (17.6%) were PAP non-adherent, one in each group of presupposition. No one had reached the aim of weight reduction (Table 2, column 5). The patients lost to follow-up, all used their PAP machines at the last follow-up consultation prior to the attempted telephone interview.

The median CollaboRATE questionnaire score was 29 (26, 30) (Table 1, Fig. 2). Mean "Observer OPTION [5]" score was 65.6 (SD 6.6, range 55−80) (Table 1, Fig. 3). The maximum score 30 in the CollaboRATE questionnaire were found in 8 of 17 observations. The correlation between SDM assessed by self-report and by rating scale was low, with Pearson's r = 0.09. There was a ceiling effect with the maximum score being scored by 8 patients.

4. Discussion

Phenotyping by SDM was found to occur, but the patient perspective was discussed to a small extent. We found high scores on the CollaboRATE and "Observer OPTION5" instruments, meaning that SDM did happen between doctors and patients with newly diagnosed OSA. The relation between SDM assessed by self-report and by a rating scale was weak and may indicate assessment of different constructs. Finally, PAP adherence was good. However, none of 14 patients motivated for weight reduction reached this treatment aim without further support. The latter is in accordance with previous literature [38].

Until recently, SDM has received little focus in sleep medicine. However a narrative review published in 2018 called for patient

centered care in OSA treatment [39]. The results reported in a recent article by Khan et al. suggest that a multifaceted patient-centered intervention based on SDM with caregiver engagement improve PAP adherence [23]. This supports the importance of exploring the patient perspective in meeting with patients and thereby identifying patients willing to actively cope with their disease. In the study by Khan et al., it is possible that caregiver engagement led to improved PAP adherence; however it is uncertain which part of the intervention made an effect. It is also unclear which components of SDM were used in the multidimensional treatment framework. The group sessions, described in more detail in the qualitative feasibility study [40], were conducted after the time of OSA diagnosis and the treatment decision with PAP was made. This is a major difference from our study, where we assessed phenotyping by SDM in video filmed consultations at the time of diagnosis. Moreover, our descriptive finding of a sub-optimal exploration of the patient perspective in communication-trained doctors indicates that the construct of SDM should be further developed and manualized before being used as a phenotyping tool in future studies requiring active coping.

Patient factors may influence treatment choices and adherence to the chosen therapy. Patients with OSA are phenotypically different and have individual needs, preferences and values that affect treatment decisions [39]. The content in our study shows that despite negative or neutral presupposition, all patients tried PAP when it was recommended by the doctor. It was typical that when the patient's presupposition was positive, the doctor encountered this with little opposition. According to Landmark et al. [41], the doctors may see it as their role to change the patient's decision towards being more congruent with the doctor's stance. Exploring and checking patient's preferences and values may function as a device to delegitimize the patient's stance and indirectly convey the doctor's opposite stance. The doctor, who expressed that his challenge was to convince the patient to PAP treatment, illustrates an example of a potential situation of disagreement. The doctor uses the patient's job as motivation for treatment. The principle that the patient "chooses" what the doctor "recommends" may be a consequence of this practice and is not identified in existing measurements tools of SDM [21,41].

We found a high adherence to PAP treatment at follow up in line with the upper range of that of previous studies [18,37]. However, even though 14 of 18 patients were also recommended a weight reduction of 10%, this decision was hardly addressed in the consultations. Moreover, no referrals to weight reduction regiments were done, despite that all participants were severely obese with a mean BMI of 35.7. No participants obtained a weight goal of 10% reduction. This is an important post hoc finding as both OSA and obesity are risk factors for cardiovascular disease and our results emphasize the importance of exploring also weight reduction when a combined treatment is recommended.

To the best of our knowledge, our study is the first using video recording to describe phenotyping by SDM between doctors and patients with newly diagnosed OSA. A high degree of SDM was found both when assessed by self-report and by rater based scoring compared to studies of non-OSA populations [42,43]. A study completed in German primary care practices regarding type 2 diabetes, chronic back pain, depression and other diseases, found an "Observer OPTION [5]" mean total score of 11.8[43]. Our study is different in several aspects, including study population and that the doctors in our study performed a communication course before study start. Existing literature has shown that several organizational and system level factors influence the implementation of SDM, including the extent to which SDM is included in medical training [44]. It is possible that ENT doctors who treat OSA and consented to be video filmed are particularly motivated to use SDM

Table 2
Content analysis of the video recordings and adherence at follow up (N = 18).

Patient's presupposition at the time of OSA diagnosis	Patient perspective	Doctor's response	Treatment decision	Adherence after six years
Positive (12) REI: 11.5 The patient wants treatment for his snoring. P: My wife says that I snore a lot and we have not slept in the same room in two years.	P: My brother has a machine and my father has had it for many years. D: It looks like you want to qualify for a PAP. Treatment is recommended. Weight reduction and tonsillectomy may reduce the need for PAP. Are your brother and father satisfied? P: It's a whole new life for them, they say.	The doctor emphasizes that PAP makes little noise and helps with snoring so that he can safely move into the same room as his wife again. The doctor does not say anything about the negative aspects of PAP treatment.	PAP + aim of 10 % weight reduction within six months.	Uses PAP 7/7 nights, almost all sleep time. The aim of weight reduction has not been achieved.
Positive (14) REI: 25.7 The patient wants treatment for his ailments. D: What do you think about it? Do you want to try it? P: Yes, anything that can improve my everyday life. As it is now, I do not work. When I wake up in the morning, I am dizzy.	P: I have been tired and weary. I have never been rested in 15-20 years. I feel like I have poor sleep quality. When I wake up in the morning I am not rested. D: Have you heard of PAP? P: Yes, my father had to use it.	The doctor says that the average oxygen uptake of the patient is reduced at night and that it is the cause of fatigue during the day. The doctor describes an increased risk of CVD in patients with OSA and obesity. The doctor explains that treatment with PAP has an immediate preventive effect for the patient.	PAP + aim of 10 % weight reduction within six months.	Uses PAP 6/7 nights, all sleep time. The aim of weight reduction has not been achieved.
Positive (15) REI: 8.7 The patient says he is motivated. D: Have you heard of PAP before? P: Yes, I have heard of it and know someone who was overweight and got it. That helped him. He gained weight because he had the energy to be more active. I'm totally ready to try it.	P: I work shifts. One week during the day and one week during the evening. The patient says that he falls asleep quickly, but that he wakes up, for example, by moving. The patient says that he has ambitions to walk more and be more physically active. D: You describe that you have restless, tingling legs. P: Yes, that's right. She I live with says so.	The doctor describes an increased risk of CVD in the patient. D: I think you benefit from using PAP to get an overpressure to counteract breathing stops and at the same time lose weight.	PAP, no commitment to weight reduction.	Uses PAP 7/7 nights, almost all sleep time. The weight reduction has not been achieved.
Positive (17) REI: 85.7 P: I am willing to try anything that can improve my everyday life. As it is now, I do not work. When I wake up in the morning, I am dizzy.	P: My wife has experienced that I have stopped breathing many times. She has experienced that I suddenly gasp for breath and sit on the edge of the bed without knowing it myself many times. D: How is the shape during the day? P: Worn out.	D: PAP is something we can do for you. Have you heard of it? Do you know anyone who uses it? P: Have heard that it can have a good effect. I have not seen anyone, no one I know . The doctor describes the preventive health effect with immediate start. D: What do you think about it? P: I want to try it.	PAP + aim of 10 % weight reduction within six months. .	Stopped PAP after 2 months. The aim of weight reduction has not been achieved.
Neutral (1) REI: 35.9	The patient has Crohn's disease and is tired during the night. D: What do you think we can do for you? P: Do not know. That you can help me in some way. Little emerges from the patient perspective through the consultation. D: One possibility is to operate the tonsils. Another solution when you have so many breathing stops is always PAP treatment. Have you heard of it? Do you know anyone who uses it? P: I've heard of it, but not seen it. I do not know anyone.	The doctor explains that the goal is to breathe well through the night. He recommends that the patient try PAP treatment first but describes tonsillectomy as a possibility eventually. D: That's what I have to say about it. The most important thing is what you say to it. P: That sounds nice. D: Do you want to try it? P: Yes.	PAP + aim of 10 % weight reduction within six months.	Uses PAP 7/7 nights, almost all sleep time. The aim of weight reduction has not been achieved.
Neutral (2) REI: 52.4	D: What is your main problem that makes you come to me? P: Social discomfort. Those around me react and have difficulty sleeping because I snore so much. I can fall asleep during the day, for example on long courses. D: Do you know anyone who uses or has such a PAP? P: Yes, and they say that it has been a slightly different life after that. Two that I know have been positive about it.	The doctor says that the sleep registration showed much breathing stops at night and that treatment is needed for that. P: Unfortunately, I have back pain, prolapse (…) D: Do you think it does not work for you? P: I think it will work better, but I think I wake up a little from the pain as well. At the same time, I think I can get better with a mask that can give me some oxygen and such. We have a number of organs that should preferably have oxygen and not struggle so solitary. D: Agree with you. You should try such a mask.	PAP, no commitment to weight reduction In addition, nasal surgery is planned and the doctor orders CT images and arranges control.	Lost to follow-up. Uses PAP 6/7 nights, almost all sleep time by consultation after 4.5 years.
Neutral (3) REI: 18.1	D: Do you know the condition? P: I don't really notice anything about it	D: The advantage is that PAP keeps the air column up and counteracts respiratory		Uses PAP 7/7 nights, all sleep time.

Table 2 (*continued*)

Patient's presupposition at the time of OSA diagnosis	Patient perspective	Doctor's response	Treatment decision	Adherence after six years
	myself. *D: Have you seen it in the newspaper or read anything about it?* *P: No, I do not have that.* *D: Do you know PAP?* *P: No, I do not.*	*arrest. It's not as uncomfortable as it sounds. In some people, PAP revolutionizes their lives; they get a new everyday life. While some do not accept it.* *D: For those who choose to try, I tend to say that they should go in with the "This is what we are going to do"- attitude. We have to try it. (…) Ultimately, you are the "lady in your own life". You decide. How do you approach it?* *P: It's okay to try.*	PAP + aim of 10 % weight reduction within six months.	The aim of weight reduction has not been achieved
Neutral (5) <u>REI: 25.6</u>	*D: What do you think we can do for you?* *P: I do not really know. I do not know anything about this here. It was my general practitioner who said I should do it.* The patient says he has a "stomach acid problem". *D: We think you need some treatment for this (OSA). The first thing we think of is a breathing mask. Have you heard of it?* *P: Yes, I've heard of it.* *D: Do you know anyone who uses it?* *P: No.*	*D: All wives and cohabitants are happy with the machine and make sure that the men use it.* *P: Yes, yes, yes.* *D: I recommend you try PAP. It does not oblige you to keep it at any cost.* *P: Then it's fine. Where can I get one like that?* *D: Are you interested?* *P: Yes. Yes.*	PAP + aim of 10 % weight reduction within six months.	Uses PAP 6/7 nights, almost all sleep time. The aim of weight reduction has not been achieved.
Neutral (6) <u>REI: 17.3</u>	*D: It says (in the reference) that your wife has sent you here.* me. *P: She says I stop breathing at night so she pushes me. I notice nothing, am not tired or headaches in the morning.* It turns out that there are several in the patient's family who have died early of heart disease. *D: Sleep apnea often presents with short-term symptoms. In the long run, the risk of cardiovascular disease increases. The low oxygen content in the blood causes unnecessary stress to the heart.* *In your case, high cholesterol, family history and a little overweight are risk factors for cardiovascular disease. Respiratory arrests increase the risk as well.*	*D: The breathing mask reduces the risk of cardiovascular disease. The alternative is to lose weight. It's not always that easy. So, I would suggest that we try such a mask and see. That does not mean you cannot lose weight at the same time. It's even better.* *P: We can do that.* *D: The downside is that you have to get used to sleeping with it (PAP). Many say that they have a whole new life afterwards, especially those who are very tired. It is clearly the best treatment.*	PAP + aim of 10 % weight reduction within six months.	Lost to follow-up. Used PAP 7/7 nights by consultation after 6 months.
Neutral (8) <u>REI: 28.6</u>	*D: What is your main problem?* *P: I do not really have any problems at all. I have atrial fibrillation and the cardiologist wanted me to check this out.* The patient has already started to lose weight. *D: We have registered a number of respiratory arrests. Oxygen uptake falls when breathing stops and the condition needs or requires treatment due to consequences such as pronounced symptoms eventually and heart problems.*	The doctor explains how PAP works. *D: What do you think about it?* *P: If you mean it then. I'm curious if I can sleep with it. It will probably become a habit and …* *D: You decide. I think you should try. You may notice a big difference and then the motivation will increase. You may feel improvement in symptoms and increased energy,* *P: Then we have to try it*	PAP + aim of 10 % weight reduction within six months.	No, stopped with PAP after 3 months.
Neutral (10) <u>REI: 33.8</u>	The patient says that he is very tired and exhausted during the day. *D: Has anyone else noticed that you stop breathing at night?* *P: My wife has said that.*	*D: All this indicates that you have bad breath at night and will need help. We recommend a breathing mask as a first choice. Have you heard of it?* *P: Yes, I have heard of it.* The doctor explains that all the respiratory arrests will disappears with PAP and he will receive good shape during the day etc. *D: What we can do for you is to call you to a new appointment to try PAP (…) What do you think about that?* *P: I am positive to try it.*	PAP + aim of 10 % weight reduction within six months	Uses PAP 4/7 nights, almost all sleep time. The aim of weight reduction has not been achieved.
Neutral (11) <u>REI: 12.7</u>	The patient sleeps poorly and is not rested when he wakes up. He snores and has a stuffy nose. The nasal congestion is not seasonal and a negative allergy test has been performed.	*D: Do you want to do something about the nasal congestion?* *P: Yes, because I cannot blow the nose and there is no reason for it.* *D: We can try to do something about that.*	Primary surgery of the nose. No commitment to weight reduction Agreement to consider PAP at the	Has not tried to use PAP in the last 6 years.

Table 2 (*continued*)

Patient's presupposition at the time of OSA diagnosis	Patient perspective	Doctor's response	Treatment decision	Adherence after six years
		follow-up consultation.		
Neutral (18) REI: 11.0	*D: What is the main reason why you come to us?* *P: I struggle with high blood percentage. I am followed up at the outpatient clinic and mentioned snoring …* *D: How is your shape during the day?* *P: All right until after dinner.*	*D: What is recommended in the first place is PAP.* *P: My dad uses it. He has the same problem.* *D: Is he satisfied? Does he use it?* *P: Yes.* *D: We think you should try it.* The patient responds that he cannot have the window open at night when using PAP.	PAP + aim of 10 % weight reduction within six months.	Uses PAP 7/7 nights, almost all sleep time. The aim of weight reduction has not been achieved.
Neutral (16) REI: 20.5	The patient is pronounced sleepy, dizzy, never rested and says that his health has become poor. *D: Have you considered that you may have such a disease?* *P: Others have told me that I stop breathing. (…) I cannot remember the last time I had a good night sleep.*	The patient has gone to the doctor without feeling that he has been taken seriously. The patient uses sleeping medication and scores high on anxiety and depression. *P: Isn't it difficult to sleep with a mask?* *D: It's a challenge. The nurses will guide you. It is wise to spend time as it takes weeks to get used to. PAP reduces the risk of cardiovascular disease and relieves sleepiness.* *P: Yes, I need it.*	PAP, no commitment to weight reduction	Lost to follow-up, but used PAP 2/7 nights by consultation after 3 months.
Negative (13) REI: 12.0 *D: You should try PAP treatment provided you are motivated.* *P: Then I would rather lose weight.*	The patient has a congenital heart defect, some overweight, little activity and poor oxygen uptake at night. *D: Do you have any questions?* *P: Not really. Does a cold have any effect on the result of the registration?* *D: No.*	*D: PAP gives you extra oxygen; you get better from the symptoms during the day right away without committing to keep it. I recommend trying it. What do you think about that?* *P: Yes, I just see that … I have four friends who use that kind of PAP.* *D: What do they say?* *P: One is not good at using it. Number two is good at using it. She is good at taking care of herself, you might say.* *D: What group are you?* *P: I'm not that careful, I think.* *D: It can be good to get more oxygen which gives more energy during the day.* The patient agrees to try.	PAP + aim of 10 % weight reduction within six months.	No, stopped with PAP after 3 months. The aim of weight reduction has not been achieved.
Negative (4) REI: 6.2 *D: It is up to you whether you want to take the opportunity to try PAP. What do you think yourself?* *P: Yes ….* *D: You seem a little insecure. What are you most skeptical about? Do you find it uncomfortable? What is most frightening?* The patient reveals a belief that he must sleep with a probe through his nose. The doctor clears up the misunderstanding.	*P: I think I breathe more with my mouth than my nose.* *D: You do not have to worry about that. There are masks that cover only the nose and both mouth and nose.*	*D: It's worth trying. It is important that your wife agrees. It's good for the family life too. You will sleep quietly and be in better shape during the day. What shall we do?* *P: Make an attempt.* The doctor describes that there are almost 50,000 users of PAP in Norway. Some are very satisfied and some are not.	PAP + aim of 10 % weight reduction within six months.	Uses PAP, but the use has varied recently according to the patient. The aim of weight reduction has not been achieved.
Negative (7) REI: 18.8 *D: What I'm most worried about is cardiovascular disease. I think we need to do something about that number, try to bring it down.* *P: What do you do then?* *D: The fastest way is PAP.* *P: I will not use that.*	The patient sleeps many nights in tent throughout the year. The patient is sent for examination because he snores. The patient denies symptoms during daytime or sleep problems. *D: In the long term, OSA increases the risk of cardiovascular disease.* *P: There I am relatively hereditarily burdened from before.*	*D: You have been sent here to assess whether you have respiratory arrest at night.* *P: It is possible.* *D: You have more breathing stops than it should be.* The patient finally agrees to try PAP. *D: Remember that it is a long-term investment, especially for you with family history of cardiovascular disease.*	PAP + aim of 10 % weight reduction within six months.	Uses PAP 7/7 nights, all sleep time. The aim of weight reduction has not been achieved.
Negative (9) REI: 104.0 *P: That was what I thought: That I should not do this (meaning not being referred).*	The patient has no symptoms. The doctor uses the new driving license regulations that soon come as motivation for treatment. The patient is dependent on it in his job. *D: Do you know about PAP?* *P: No.*	*D: With those values of yours (on the sleep registration), we know that the chance of other diseases is high.* *P: I have no symptoms.* *D: It is like having high blood pressure. You do not have to have symptoms, but you know it is unfavorable not to do something about it. It is challenging to use treatment when you do not feel sick.* *D: It is my challenge to try to convince you.*	PAP + aim of 10 % weight reduction within six months.	Uses PAP 7/7 nights, almost all sleep time. The aim of weight reduction has not been achieved.

Table 2 (*continued*)

Patient's presupposition at the time of OSA diagnosis	Patient perspective	Doctor's response	Treatment decision	Adherence after six years
		You are a young man, relatively. Having such high values over a long period of time is so unfavorable that the alternative with treatment is better. The patient agrees to try PAP.		

D: Doctor, P: Patient, OSA: Obstructive sleep apnea; PAP: Positive airway pressure, REI: Respiratory event index.
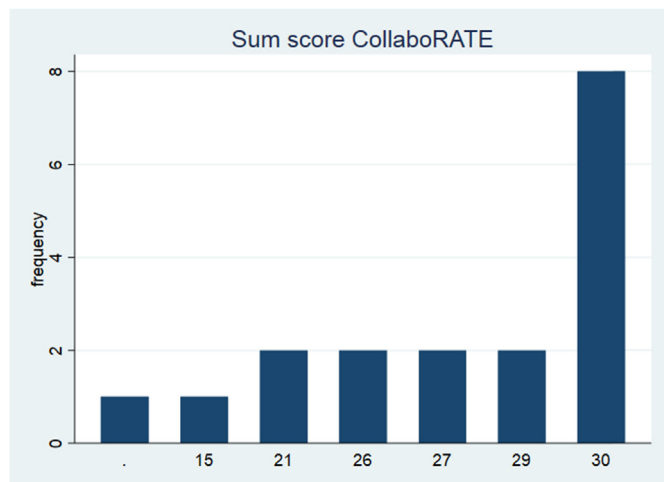

Fig. 2. Scoring with the CollaboRATE questionnaire. OSA, video filmed. N = 17, (1 missing).
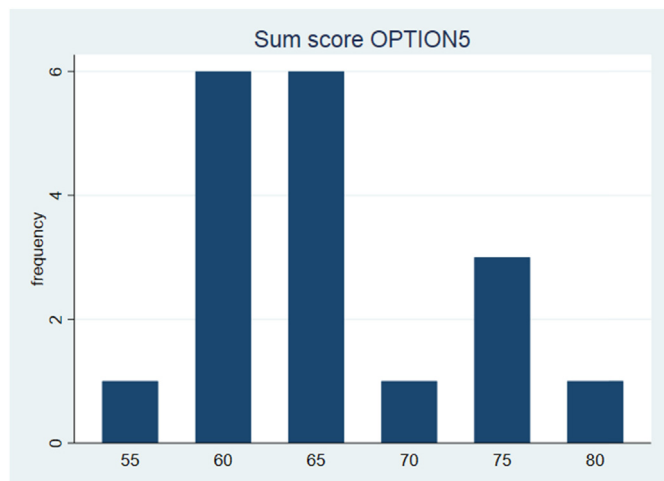

Fig. 3. Scoring with "observer OPTION5". N = 18.

because PAP is such a demanding treatment where patient participation is the key to success.

Despite the high score of SDM assessed by "Observer OPTION [5]", the relation between self-report and rating scale was weak. Our result is in line with those of other studies reporting weak relation between self-report questionnaires and rating scale [45,46]. Moreover, the CollaboRATE questionnaire also performed suboptimal due to a ceiling effect. Accordingly, the data distribution was skewed towards a positive evaluation of doctor's performance. Other patient-reported questionnaires have shown a similar trend where the views of expert observers were in conflict with favorable

assessments of doctors from patients [47]. Our study supports the importance of more validation studies of measurements of SDM and the content of SDM in sleep medicine per se.

4.1. Strengths and limitations

This study has several strengths. It is a mixed-method study of phenotyping by SDM with qualitative content analysis and quantitative data, both by self-report and by a rating scale. The consultations were video recorded, allowing for in-depth analysis of the doctor-patient interactions.

There are also limitations to consider: A low proportion of patients and doctors consented to be video filmed. We do not have precise data on their concerns or data on the doctors who were approached but did not accept. Also oversampling on BMI created a sample with more need of treatment than the overall, clinical cohort. We did not complete a self-reported measurement of SDM by the doctors after the consultations. Only 18 of 89 eligible consultations were videotaped and we can therefore not exclude potential selection bias. However, we did not find any significant differences other than BMI, between participants and non-participants on variables considered important for outcomes. PAP adherence and weight goal assessments were based on self-report only and not objective data due to the Covid-19 pandemic. Unfortunately we did not have access to a structured weight loss program or other treatment options.

5. Conclusion

Despite a high degree of SDM compared to studies of non-OSA populations, the sub-optimal exploration of the patient perspective by communication-trained doctors precluded identification of patients willing to cope actively. SDM assessed by self-report and by a rating scale may represent two different constructs. PAP adherence was good.

Credit Author Statement

All authors made substantial contributions to the conception or design of the work. Caroline Tonje Øverby (CTØ), Pål Gulbrandsen (PG), Toril Dammen (TD) and Harald Hrubos-Strøm (HH) planned the paper and analysis. CTØ and Prasanthy Sutharshan (PS) performed the analysis of SDM by assessing the video recordings. Data analysis, figure and tables were performed by CTØ. CTØ drafted the first manuscript draft. All the authors contributed to the revisions of the manuscript and read and approved the final version of this manuscript before submission.

Declaration of competing interest

None.

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Abbreviations

OSA	obstructive sleep apnea
SDM	shared decision making
AHI	apnea-hypopnea index
REI	respiratory event index
ODI	oxygen desaturation index
AASM	American Academy of Sleep Medicine
BMI	body mass index

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