National Institute for Health and Care Excellence

Draft

Obstructive sleep apnoea/hypopnoea syndrome and obesity hypoventilation syndrome in over 16s

Evidence review O: Information and support

NICE guideline

Qualitative evidence review

March 2021

Draft for Consultation

Developed by the National Guideline Centre,
hosted by the Royal College of Physicians

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1.1 Review question: What information and support do people and their families or carers need (for example, advice on lifestyle, driving and occupation, and their treatment)?

1.2 Introduction

NICE has developed guidance on patient experience in adult NHS services that includes recommendations on information for patients (CG138). It is also important to identify and address the unique needs of people who are being considered for a diagnosis of obstructive sleep apnoea/ hypopnoea syndrome (OSAHS), obesity hypoventilation syndrome (OHS) or COPD-OSAHS overlap syndrome, and those who have a diagnosis of OSAHS, OHS or COPD-OSAHS overlap syndrome and are receiving care and monitoring. Currently some of this information is available on national websites, such as the Sleep Apnoea Trust Association, the British Lung Foundation, the Drivers and Vehicle Licensing Association (DVLA). Each hospital may have its own locally written information to distribute to patients in clinic or for example when commencing CPAP therapy. This local information may differ between centres, reflecting local practice, but there is no national standard for this information.

An evidence review was undertaken to try to find out what specific information people with OSAHS, OHS or COPD-OSAHS overlap syndrome should be given.

For full details see the review protocol in appendix A.

1.3 Characteristics table

Table 1: PICO characteristics of review question

Objective	To find out through qualitative research what information and support people (and their carers and healthcare professionals) need
Population and setting	People with OSAHS/OHS/COPD-OSAHS overlap syndrome, their family/carers and healthcare professionals involved in their care Evidence will be stratified by: • OSAHS vs OHS vs COPD-OSAHS overlap syndrome
Context	Information and support needs as described by studies
Review strategy	Synthesis of qualitative research. Results presented in narrative format. Quality of evidence assessed by a GRADE CerQual approach for each review finding

1.4 Qualitative evidence

1.4.1 Included studies

OSAHS

Twenty five qualitative studies were included in this review;[7, 8, 10, 11, 13, 15, 17, 20, 23, 24, 32, 33, 44, 46-49, 51-58] this is summarised in Table 2 below. All studies included in the review were looking at adult patients with OSAHS.

This review covered following themes:

- type and format of information
- communication between patients and healthcare professionals

- experiences of CPAP use
- factors influencing behaviour change
- factors influencing seeking treatment
- factors influencing partners support.

There were no studies identified about advice on driving and occupation.

OHS

There were no studies identified looking at patients with OHS.

COPD-OSAHS overlap syndrome

There were no studies identified looking at patients with COPD-OSAHS overlap syndrome.

1.4.2 Excluded studies

See the excluded studies list in appendix E.

1.4.3 Summary of clinical studies included in the evidence review

Table 2: Summary of studies included in the evidence review

Study	Design	Population	Research aim	Comments
Brostrom 2010[8] Sweden Qualitative study	In depth interviews. A qualitative content analysis was employed.	N=23 patients with OSAHS Age –mean (range) Men – 59 (33-73) Women -62(45-74)	To explore the experiences of adherence to CPAP treatment in patients with OSAS.	High quality of evidence
Brostrom 2017[7] Sweden Qualitative study	Interviews	N=25 patients with OSAHS Took place after their initial visit at four CPAP clinics. Age (range) 20-39 – 3 patients 40-59 – 10 patients 60-69 – 6patients >70 – 6 patients	To describe facilitators and barriers from a patient perspective in communications between patients with OSAS and healthcare personnel during the first meeting when CPAP is initiated.	High quality of evidence
Dickerson 2006[10] USA Qualitative study	Support group	N=17 people with sleep apnoea who use CPAP for treatment and attend a support group. Male/female – 12/5	Study examined help-seeking experiences in support groups of people with sleep apnoea who use CPAP devices	High quality of evidence
Dickerson 2013[11] USA Qualitative study	Telephone interview using "talk-out-loud technique" to determine usability. The interviews transcripts were analysed thematically.	N=10 participants with sleep apnoea and varying ages, race, education and CPAP usage, found the intervention contained useful information to understand their diagnosis, to problem-solve and monitor their progress. Age mean (SD) – 42.7 (13.4)	Development and usability testing of a self-management intervention to promote CPAP adherence.	High quality of evidence
Elfstrom 2012[13] Sweden	A qualitative descriptive design using critical incident technique was used. A total of 542	N=25 strategically selected partners of patients with CPAP treated OSAHS.	The aim of this study was to explore and describe decisive situations affecting	High quality of evidence

Study	Design	Population	Research aim	Comments
Qualitative study	decisive situations affecting partners' support and 222 situations describing managing were collected by means of interviews with 25 strategically selected partners of patients with CPAP treated OSAS.	Age (range) <40 – 70	partners' support to patients with OSAS and how the partners manage these situations during the initial phase of CPAP treatment.	
Firestone 2010[15] New Zealand Qualitative study	Qualitative research based on 3 focus groups	N=27 taxi drivers who had a high pre-test risk for obstructive sleep apnoea. Assignment to focus groups was based on self-identification as being Maori and Pacific peoples, New Zealand European, or non-Maori and non-Pacific. Age (range) New Zealand European – 36-66 Maori/pacific – 46-64 Other ethnicity – 40-64	To examine the attitudes of taxi drivers towards symptoms of OSAS, and to determine whether these attitudes could influence their health and safety as a professional driver.	High quality of evidence
Fung 2017[17] USA Qualitative study	Four focus groups	N=35 older sleep apnoea patients Age – all patients 65 years old or older	To explore older adults' communication with their providers, preferences for communication and views on communication attributes and decision aid characteristics, by conducting four focus groups.	High quality of evidence
Henry 2013[20] USA Qualitative study	In-depth, semi-structured interviews with both patients and partners (n = 24).	Patients clinically diagnosed with sleep apnoea were recruited by a physician. N =24 (12 patients and 12	To illuminate the significance of gender and partner-reporting in shaping the lay diagnosis, management, and	High quality of evidence

Study	Design	Population	Research aim	Comments
		spouses) participated in semi-structured interviews. Age (range) – 27 – 72	treatment of obstructive sleep apnoea	
Igelstrom 2012[23] Sweden Qualitative study	Interviews and qualitative analysis	N= 15 People with sleep apnoea and obesity. Seven women and 8 men were interviewed Age – Median (QD) - 62(8.5)	The purpose of this study was to explore aspects of engagement in physical activity in persons with obstructive sleep apnoea who were overweight.	High quality of evidence
Ingadottir 2006[24] Iceland Qualitative study	Data generated through two 1-hour semi-structured interviews with each pair of participants, were analysed into themes. Results are presented by the following narratives: (i) mixed blessing: life-saving treatment - meaningless exertion; (ii) compassion and understanding central amid use of complex machines; (iii) listening to the body; (iv) wanting to be seen as healthy; (v) dominance of technological thinking; and (vi) sustained work in maintaining the treatment.	N=6 patients that have been dependent on sleep technology in the form of non-invasive ventilation with or without long term oxygen therapy for at least 6 months due to sleep-related breathing disorders aged 45-70, five spouses and one daughter	This study describes patients' and families' experience of long-term home treatment with non-invasive ventilation during sleep with or without additional oxygen therapy.	High quality of evidence
Luyster 2016[32] USA Qualitative study	Qualitative research study. Qualitative content analysis identified five themes: knowledge of sleep apnoea, effects of sleep apnoea, effects of CPAP, barriers and facilitators of CPAP, and ideas for a new user support program. Patients and partners emphasized the importance of	N= 27 participants were collected via four sleep apnoea patient and four partner focus groups. Al patients over 21 years of age	This qualitative research study explored patients' and partners' experiences of CPAP and facilitators and barriers to CPAP use, and elicited suggestions for a first-time CPAP user program.	High quality of evidence

Study	Design	Population	Research aim	Comments
	partner involvement in the early CPAP treatment period.			
Murphy 2000[33] USA Qualitative study	Patients watched either an instructional videotape about sleep apnoea or read a newly designed brochure, then responded to a structured questionnaire containing 11 knowledge-based questions and 1 open-ended question (requesting suggestions for improvement of the brochure or videotape).	N=192 sleep apnoea patients Age (mean) by intervention: Brochure – 44 years Video – 46 years	To compare the effectiveness of video and written material for improving knowledge among sleep disorders clinic patients with limited literacy skills	High quality of evidence
Shaw 2012[44] USA Qualitative study	Five focus groups	N= 39 black men and women with OSA, aged ≥18 years	To ascertain barriers preventing or delaying OSA evaluation and treatment in black community.	High quality of evidence
Sporndly-Nees 2014[46] Sweden Qualitative study	Semi-structured interviews were conducted and data were transcribed and analysed using qualitative content analysis with researcher triangulation for trustworthiness.	N= 15 patients with OSAHS (AHI>15) and obesity (Mean body mass index 38.2). Age – mean (SD – 56.8 (10.2)	The aim of this study was to identify personal conceptions of prerequisites for eating behaviour change.	High quality of evidence
Stalkrantz 2012[47] Sweden Qualitative study	The interviews were analysed according to the Grounded Theory method as described by Strauss and Corbin.	N= 12 spouses of sleep apnoea patients Age range – 25 - 67	The aim of this study was to generate a theoretical model describing concerns for spouses of patients with untreated obstructive sleep apnoea syndrome (OSAS) and how they manage these concerns in their everyday life.	High quality of evidence
Tyrrell 2006[48] France	Semi-structured interviews, constructed from the Health Belief Model (HBM)	N=9 patients with OSA were interviewed (age 32-70 years; 8 males).	Study explored patients understanding and experiences of their OSA	High quality of evidence

Study	Design	Population	Research aim	Comments
Qualitative study			and of the CPAP therapy and their reasons for stopping treatment.	
Veale, 2002[49] France Qualitative study	Semi-directive interviews with patients attending a pulmonary rehabilitation and convalescent unit around the themes of sleep, health and treatment. An analysis of content and of discourse was carried out by textual analysis and by propositional analysis of discourse (PAD) with the aid of dedicated computer programs (Tropes, Sphinx Lexica).	N=30 patients with OSA attending a pulmonary rehabilitation and convalescent unit around the themes of sleep, health and treatment. Age range (median) – 39 -74 (55)	To seek an in-depth analysis of how patients live with sleep apnoea by allowing them an open discourse and analysing the text of their statements.	High quality of evidence
Vlachantoni 2015[51] Greece Qualitative study	Self-administered questionnaire	N= 840 taxi drivers with OSAHS. Only ten 10 participated in the qualitative study. Age- mean(SD) – 44.5 (10.35)	To evaluate the prevalence of morning and day sleepiness and OSAS among taxi drivers of the Athens airport and to examine the factors that may influence a taxi driver's decision to participate in screening.	High quality of evidence
Waldman 2020[52] USA Qualitative study	Semi structured focus groups	N=42 participants currently experiencing excessive daytime sleepiness with OSA Age – mean (range) – 51.4 (31-75)	This qualitative research examined timing and reasons patients sought medical care for their EDS and OSA symptoms, and the impact of EDS on HRQOL.	High quality of evidence
Ward 2017[54] New Zealand Qualitative study	Semi-structured interviews during four months of 2011 and six months of 2014.	N= 16 participants with sleep apnoea participated, recruited through a main-	To explore experiences of living with CPAP from participants' perspectives.	High quality of evidence

Study	Design	Population	Research aim	Comments
		centre respiratory service in New Zealand Age band: 25-35 – 2 patients 36-45 – 4patients 46 – 55 – 2 patients 56 – 65 – 6 patients 66+ 2 patients		
Ward 2018 [53] New Zealand Qualitative study	Semi-structured interviews	N=16 adult patients with sleep apnoea Age: (25-35) – 2 participants; (36 – 45) - 4 participants; (46 – 55) – 2 participants; (56 – 65) - 6 participants; (65+) 2 participants. Ethnicity: New Zealand/European - 9; Maori -1; Samoan – 1; Indian – 3; NZ European/other – 2	To explore experiences of living with CPAP therapy from participants' perspective using constructionist grounded theory.	High quality of evidence
Willman 2012[55] Sweden Qualitative study	A qualitative content analysis was employed. Fifteen participants were consecutively selected. Data were collected by semi-structured interviews.	N= 15 participants with sleep apnoea and obesity were consecutively selected. Age- mean(SD) – 56.8(10)	The purpose of this study was to describe patients' experiences of CPAP treatment in obese people with moderate to severe OSAS.	High quality of evidence
Ye 2017[56] USA	20 joint qualitative interviews	N= 20 patients with obstructive sleep apnoea	This qualitative analysis used a dyadic approach to identify facilitators and	High quality of evidence

Study	**Design**	**Population**	**Research aim**	**Comments**
Qualitative study		Age patient – mean (SD) – 49.6 (9.6) Age partner – mean (SD)- 50.1 (10.1)	barriers to successful treatment of one of the most common sleep disorders, obstructive sleep apnoea, with CPAP.	
Zarhin 2015[57] Israel Qualitative study	In depth interviews	N= 65 Israelis who received a laboratory diagnosis of OSA Age – range – 30-66 years Men age (mean) – 53.5 Women age (mean) – 57.7 Men/women – 34/31	To examine whether and how the ways in which OSA emerged affect patients	High quality of evidence
Zarhin 2017[58] Country: Israel Qualitative study	In-depth interviews	N= 61 Jewish-Israeli patients with OSA who received a recommendation to use a CPAP device. The sample includes both patients who started using CPAP devices as well as patients who rejected this course of treatment. Age – mean (SD) Non-users – 54.3(9) Adherent users – 56.8(5.6) Partially adherent – 60.5(4.4) Non adherent – 55.5(4.5) Total – 55.3(8.1) Male/female – 33/28	To understand patients experiences of CPAP use vs non use	High quality of evidence

See Appendix D for full evidence tables

1.4.4 Narrative summary of review findings

1.4.4.1 Content of information

Review finding 1: Type and format of the information (5 studies)

Brochures and videotapes. Both high level and low level readers stated that they wanted brochures and videotapes that explained treatment and outcomes information using simple terms. Patients also felt that information about outcomes is more important than pathophysiology of the disease.

Treatment options. Patients suggested more information on treatment options (they specifically requested better explanation of surgical options) and what preparation they should expect for their polysomnogram. Specific concerns about polysomnogram included the attire for testing and what would happen if they needed to get up during the night.

Feedback from other patients. Several patients wanted feedback from patients who had the same treatments.

More information - Participant responses indicated a desire to have more information when receiving the diagnosis for the first time, including an explanation of the implications of having OSA diagnosis, the risks of not adhering to therapy, and how to use the PAP device.Clarity of information. The suggestion was made to include clear and complete steps of treatments, choosing words that are simple and relative to the patient's concerns.

Ethnic representation. More ethnic representation was requested from number of patients; patients wanted to be able to identify with the patient used as an example.

New user support programme. Patients and partners suggested format options and important components that would be valuable in developing a program to help first-time CPAP users feel comfortable using CPAP. Small group sessions led by a respiratory therapist and/or a current CPAP user or an online video were identified by patients as optimal formats for providing the program.

Peer support. A number of participants suggested practical ways to disseminate information about sleep apnoea and its treatment within the community. “Organize a group. If you could go in and find out who's not sleeping and focus on them”.

Personalised information. Patients felt that it would be helpful to have treatment information tailored to their needs, including information on the negative impact of treatment on comfort and convenience and disclosure about common barriers to adherence.

Explanation of quality assessment: no methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy. There was a judgement of high confidence in this finding.

1.4.4.2 Communication between patients and healthcare professionals (2 studies)

Review finding 1: Confidence building

Structure building – Greeting the patient in an open and friendly way, when showing him or her into the room was expressed as an important structure - building aspect at the beginning of the communication process.

Information transfer - A warm and positive clarification of the reason for the visit, as made by the healthcare personnel, commonly initiated the information transfer.

Commitment – Patients felt that an understanding, but at the same time committed and informative response from the healthcare personnel, was essential to empower the patients to be active and elicit their own perspective of OSAS and CPAP at the beginning of the consultation.

Explanation of quality assessment: no methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy. There was a judgement of high confidence in this finding.

Review finding 2: Confidence hindering

Organisational insufficiency - for example a long waiting time before the appointment followed by unprepared healthcare personnel who went straight to the topic (e.g. The type of CPAP mask) without greeting the patient, or failing to explore the patient's perspective on the reason for the appointment (e.g. not asking about symptoms).

Stress behaviour/interaction deficit - This stressed behaviour, sometimes further emphasised by healthcare personnel who did not seem to know or remember the patient's specific history and needed to check the medical record several times, caused an interaction deficit that had a negative effect on the patient's confidence and negatively affected the communication at the beginning of the consultation.

Explanation of quality assessment: no methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy. There was a judgement of high confidence in this finding.

1.4.4.3 Experiences of CPAP use (8 studies)

Review finding 1: Facilitators of CPAP use

The CPAP patient's partner aiding diagnosis and treatment – participants emphasized that the positive role that the partner played in aiding the diagnosis and treatment process. Couples working together using CPAP, perceived benefits of CPAP for both partners, the patient being motivated to use CPAP for the partner, Support provided by the partner for CPAP use.

Becoming used to CPAP – patients who remained motivated and persevered with the choice to use CPAP started becoming used to CPAP. Participants made adaptations to integrate CPAP into daily life choosing new routines. Once the challenges of using CPAP had receded, getting used to CPAP became relatively straightforward. In the presence of time and perseverance, mastering CPAP became possible. CPAP became normal and routine part of life that no longer required conscious effort but retained importance in maintaining good sleep for users and partners.

Meeting adherent CPAP users - The data indicate that people who know CPAP users that are pleased with the device and use it regularly are more likely to try the device whereas people who only know nonusers are less likely to try it. Still, as the previous section described, although knowing adherent CPAP users may influence people's willingness to try PAP therapy, it does not ensure long-term Adherence.

Finding other treatment options unsatisfactory - respondents found some relief by using these alternative options, the rest said that at the time of the interview, they had not yet found an effective treatment. These respondents stated that "the next step" would be to try (or retry) the CPAP.

Getting a new life – All of the patients experienced a positive difference with CPAP and life improved in a lot of different ways – they slept better, were more alert and had more energy to do more things than before.

Explanation of quality assessment: no methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy. There was a judgement of high confidence in this finding.

Review finding 2: Barriers of CPAP use

Anxiety related to CPAP treatment - particularly in the beginning of therapy, bothersome equipment causing disruptions in sleep and bedtime routine, interruptions to intimacy, concern about image change while wearing CPAP.

Feeling uncertain about the role of CPAP in improving symptoms and quality of life - adherent CPAP users were generally pleased with the device's effects on their daytime and night-time symptoms. They felt more rested and energetic during the day and experienced fewer awakenings at night. Respondents addressed the improvement in symptoms and quality of life as one of the major benefits of the device. However, they did not credit the improvement in their condition solely to the device. Rather, they kept pondering whether other factors, such as reduced stress due to retirement or reduction in workload, as well as weight loss and exercise, contributed to their recuperation. In other words, in spite of the benefits they obtained, they were ambivalent about the exact role of CPAP in what they called their "recovery" or "improvement."

Explanation of quality assessment: no methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy. There was a judgement of high confidence in this finding.

1.4.4.4 Factors influencing behaviour change (2 studies)

Review finding 1: Physical activity

Consequences of OSA and obesity – The majority of informants were aware that OSA and obesity could lead to medical problems, such as heart disease. On the other hand, most informants stated that it did not occupy their thoughts, and there were even statements that revealed an explicit ignorance of such risks.

Positive outcomes – positive outcomes included physical and medical benefits. For example, less pain, reduced weight, and reduced risks for medical diseases were mentioned. Another positive outcome was enhanced personal well-being, expressed as positive feelings from physical activity or enhanced health.

Side effects of physical activity – were expressed as bodily sensations such as pain, exertion, or unpleasant sensations from the heart of exercising. Another unwanted side effect was lack of time or running out of time. Those mentioning this side effect expressed that they already had too much to do and that adding physical activity would only stress them further.

Ambivalence – some statements indicated ambivalence of informants regarding the outcome expectations and motivators for enhanced physical activity. Some informants described several expected outcomes, but were doubtful about obtaining them for themselves, since they had not experienced it to date.

Review finding 2: Facilitators and barriers for eating behaviour changes

Barriers – Desire and reward (needing to satisfy the desire for food and compensating the desire for tabacco), cravings and emotional control (eating as a tool to control feelings), low self-confidence (not being able to cope with the problem), insufficient support (wanting support), taxing behaviours (demanding and time cosuming), cost (too expensive), lack of knowledge about healthy eating strategies, perceived helplessness (not feeling able to affect one's own situation), and low susceptibility were considered as barriers for eating behaviour changes.

Facilitators – Positive expectations (results and expectations are motivating), fear of negative consequences (expecting consequences), experience of success (good self-confidence), support and follow up (support from family, peers and professionals), accessibility (time and readily available healthy food), applied skills for healthy eating (knowledge about healthy food), personal involvement (wanting to be in control), challenged self-image (not recognising oneself) were considered as facilitators for eating behaviour changes.

Explanation of quality assessment: no methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy. There was a judgement of high confidence in this finding.

1.4.4.5 Factors influencing seeking for treatment (5 studies)

Ignorance - Ignorance was defined as a lack of awareness about the underlying causes of sleepiness, and the potential risks of sleepy driving, and a lack of knowledge about the availability of treatment services for OSAS. It included both driver ignorance and ignorance among medical professionals. The following excerpts typify driver ignorance.

Personal fear - was characterised by patients not wanting to believe that something is physically wrong, or being apprehensive about finding out about further or more serious health conditions that could compromise their ability to earn a living. A common element in this sub-theme was mistrust of other people’s concerns about the driver’s health.

Environmental Barriers to Evaluation for Obstructive Sleep Apnoea - When asked about barriers to having an overnight assessment for sleep apnoea, participants’ responses focused on environmental factors such as sleeping in a strange environment, being watched while they sleep, and not having a clear understanding of what the sleep assessment entails.

Attitudes towards their personal health - Drivers were found not to consider personal health a priority and as a consequence, to dedicate little or no time on maintaining it. Drivers described taxi-driving jobs in general as a profession that leaves little or no time for extra-curricular activities. Work is generally prioritized over family time

Patients’ reception of OSA diagnosis - While most of the participants did not reject their diagnoses completely, about a third expressed doubts and scepticism towards it. Some ‘doubters’ tended to prioritise symptoms (especially daytime sleepiness), and clinical signs (particularly obesity), implicitly or explicitly criticising the exclusion of these factors from the definition of OSA while relying on a specific image of the OSA patient as sleepy and obese. Other patients also disapproved of the diagnostic procedures and technology by suggesting that ‘laboratory sleep’ is not an accurate indicator of their quality of sleep at home.

Reasons for seeking medical care - the primary reasons were due to input from spouse/partner, another family member, or friend, the participant’s own concern about particular symptoms and/or falling asleep while driving. Small numbers also reported seeking medical attention due to having a comorbidity, falling asleep at work, having a car accident due to EDS, being required by an employer, and seeing a sleep study advertisement.

Explanation of quality assessment: no methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy. There was a judgement of high confidence in this finding.

1.4.4.6 Factors influencing partners’ support (4 studies)

Decisive situations influencing support negatively – 5 categories of decisive situations influencing support negatively, as described by partners, were identified: adverse effects (problems with the mask, feelings of panic and impaired sleep), limited effect (continuing symptoms and disappointment), practical and physiological problems (complicated routines, difficulty of using CPAP, shame, inhibited closeness), limited presence (being fatigued and being occupied) and initiation routines perceived as inappropriate (poor accessability, non-participation in CPAP tryout, poor knowledge).

Decisive situations influencing support positively- 4 categories of decisive situations influencing support positively, as described by partners, were identified: Well-functioning treatment (easy manageable routines, established habits), improvements (decreased number of apnoeas, improved sleep, increased alertness), high motivation (positive attitude to CPAP, understanding the risk of apnoeas andsecondary diseases) and support from friends,family and healthcare personnel.

Managing of decisive situations – 4 categories of managing decisive situations that influenced the partners' support were identified: letting the patient handle the treatment himself/herself (handling over practical aspects of treatment: avoid to help patient with routines and telling patient to adjust mask by himself/herself); helping patient to take responsibility for the treatment (giving advice so the patient can evaluate and solve problems by himself/herself, reminding the patient to clean the mask properly); handling of treatment together (showing supportive attitude so the treatment is used: providing positive encouragement about the positive effects of the treatment and supporting an openconversation with friends/family); and taking over handling of the treatment from the patient (making sure that treatment works practically: preparing the device, resolving problems and supervising that the device works). The same partner used different types of behaviours in different situations if needed.

Iconic cultural status of snoring, particularly for men, became evident in interviews. For male patients in particular, , comical representations of snoring in the popular culture made it difficult, and embarrassing, for them to talk about it seriously, and because of this perception, wives often struggled to push their partner to accept that their style of snoring was not normal.

Because of this perception, wives often struggled to push their partner to accept that their style of snoring was not normal.

Snoring in women - For women whose snoring might indicate apnoea, a different kind of danger became apparent, that “considerate” male spouses could feel compelled to downplay or underreport the symptom, as it's not considered something that women are supposed to do. Male spouses could feel compelled to downplay or underreport the symptom of snoring, as it is not considered something that women are supposed to do.

Social adjustment - Social adjustment' includes two categories that reveal different reactions to adjustments required by their partners' symptoms. The first category ‘Limited circumstances' describes a feeling of lack of control, i.e. social adjustments. This could mean that they experienced limited time for their daily activities, e.g. on those days that their partner was tired, they received less help at home. The spouses also felt that the time for their own activities was decreased. The second category, ‘same circumstances', conversely describes how the spouses were able to see the social adjustments as less of an issue of lack of control and more as a challenging circumstance requiring compromise.

Sacrificing - Sacrificing was one way of managing everyday life for the spouses family and missed the support from their partners in getting help with everyday chores. The sacrifices the spouses did were connected with their partner's tiredness and its consequences, but even their own tiredness led to their not having as much energy as earlier.

Controlling - Controlling was another way of managing the life situation. The spouses felt they needed to have control, in everyday life, as well as during the night, in relation to their partner's OSAS. Control was their own choice, but was perceived as a necessity in relation to the worry and anxiety they felt about their partner's OSAS symptoms.

Changing - Changing was also a way of managing the everyday life. To make do different types of changes could help both the spouses, as well as their partners. The spouses expressed both fear and anxiety about the future, both concerning their own and their partner's health.

Understanding - Understanding meant that even how hard it was for the spouses in their everyday life, it was important to have an Understanding for their partners OSAS, as a way of managing the situation. Despite the anger over not being able to sleep properly and tiredness during the day, the spouses still described feelings of empathy as they felt sorry for their partner, because it was not his/her fault to suffer from OSAS. 'It must be dead tough'.

Explanation of quality assessment: no methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy. There was a judgement of high confidence in this finding.

1.4.5 Qualitative evidence summary

Table 3: Summary of evidence – Type and format of the information

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
5 studies (303 patients) Dickerson 2013[11] Murphy 2000[33] Luyster 2016[32] Shaw 2012[44] Fung 2017[17]	Semi structured interviews	Patients mentioned these types and formats of information that would be useful for making decisions: **Brochures and videotapes** that explain treatment and outcomes information using simple terms. Treatment options - Patients suggested more information on treatment options **Feedback from other patients** - Several patients wanted feedback from patients who had the same treatments. **Clarity of information**- The suggestion was made to include clear and complete steps of treatments, choosing words that are simple and relative to the patient's concerns **Ethnic representation**- More ethnic representation was requested from number of patients; patients wanted to be able to identify with the patient used as an example. **New user support programme** - Patients and partners suggested format options and important components that would be valuable in developing a programme to help first-time CPAP users feel comfortable using CPAP. Small group sessions led by a respiratory therapist and/or a current CPAP user or an online video were identified by patients as optimal formats for providing the program. **Peer support** - A number of participants suggested practical ways to disseminate information about sleep apnoea and its treatment	Limitations	No concerns about methodological limitations[a]	High
			Coherence	No concerns about coherence[a]	
			Relevance	No concerns about relevance[a]	
			Adequacy	No concerns about adequacy[a]	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
		within the community. “Organize a group. If you could go in and find out who’s not sleeping and focus on them”. **Personalised information**- Patients felt that it would be helpful to have treatment information tailored to their needs, including information on the negative impact of treatment on comfort and convenience and disclosure about common barriers to adherence.			

(a) Risk of bias was assessed using the CERQual checklist.

Table 4: Summary of evidence – communication between patients and healthcare professionals

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
2 studies (60 patients) Brostrom 2017[7] Fung 2017[17]	Interviews and focus groups	People mentioned confidence building and confidence hindering information which affects communication between them and healthcare professionals. **Confidence building factors:** structure building, information transfer, desire for more information, and commitment. **Confidence hindering factors:** Organizational insufficiency, stress behaviour/ interaction deficit.	Limitations	No concerns about methodological limitations[a]	High
			Coherence	No concerns about coherence[a]	
			Relevance	No concerns about relevance[a]	
			Adequacy	No concerns about adequacy[a]	

(a) Risk of bias was assessed using the CERQual checklist.

Table 5: Summary of evidence – experiences of CPAP use (facilitators and barriers)

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
8 studies (168 people) Brostrom 2010[8] Dickerson 2006[10] Dickerson 2013[11] Ward 2017[54] Willman 2012[55] Ye 2017[56] Zarhin 2017[58] Ingadottir 2006[24]	Unstructured interviews/support groups	**Facilitators of CPAP use:** The CPAP patients' partner aiding diagnosis and treatment, Becoming used to CPAP, Meeting adherent CPAP users, Finding other treatment options unsatisfactory, Getting a new life. **Barriers of CPAP use:** Anxiety related to CPAP treatment particularly in the beginning of therapy, bothersome equipment causing disruptions in sleep and bedtime routine, Interruptions to intimacy, Concern about image change while wearing CPAP	Limitations	No concerns about methodological limitations[a]	High
			Coherence	No concerns about coherence[a]	
			Relevance	No concerns about relevance[a]	
			Adequacy	No concerns about adequacy[a]	

(a) Risk of bias was assessed using the CERQual checklist.

Table 6: Summary of evidence – Factors influencing behaviour change

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
2 studies (30 people) Igelstrom 2012[23] Sporndly-Nees 2014[46]	Semi-structured interviews	People mentioned factors influencing behaviour change (both for physical activity and eating behaviour changes) **Factors influencing physical activity -** Consequences of OSA and obesity, positive outcomes, side effects of physical activity, ambivalence, facilitators for success and challenges to overcome. **Facilitators and barriers for eating behaviour changes:** **Barriers** – Desire and reward, cravings and emotional control, low self-confidence, insufficient support, taxing behaviours, cost, perceived helplessness, low susceptibility. **Facilitators** – Positive expectations, fear of negative consequences, experience of success, support and follow up, accessibility, applied skills for healthy eating, personal involvement, challenged self-image	Limitations	No concerns about methodological limitations[a]	High
			Coherence	No concerns about coherence[a]	
			Relevance	No concerns about relevance[a]	
			Adequacy	No concerns about adequacy	

(a) Risk of bias was assessed using the CERQual checklist.

Table 7: Summary of evidence – Factors influencing seeking for treatment

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
5 studies (171people) Shaw 2012[44] Vlachantoni 2015[51] Zarhin 2015[57] Firestone 2010[15] Waldman 2020[52]	Focus groups/support groups/semi-structured interviews	**Ignorance –** ignorance was defined as a lack of awareness about the underlying causes of sleepiness, and the potential risks of sleepy driving, and a lack of knowledge about the availability of treatment services for OSAHS. It included both driver ignorance and ignorance among medical professionals. **Personal fear** – was characterised by patients not wanting to believe that something is physically wrong, or being apprehensive about finding out about further or more serious health conditions that could compromise their ability to earn a living. A common element in this sub-theme was mistrust of other people's concerns about the driver's health. **Environmental barriers to evaluation for obstructive sleep apnoea** – when asked about barriers to having an overnight assessment for sleep apnoea, participants' responses focused on environmental factors such as sleeping in a strange environment, being watched while they sleep, and not having a clear understanding of what the sleep assessment entails. **Attitudes towards their personal health** – drivers were found not to consider personal health a priority and as a consequence, to dedicate little or no time on maintaining it. Drivers described taxi-driving jobs in general as a profession that leaves little or no time for extra-curricular activities. Work was generally prioritised over family time **Patients' reception of OSA diagnosis -** While most of the participants did not reject their diagnoses completely, about	Limitations	No concerns about methodological limitations[a]	High
			Coherence	No concerns about coherence[a]	
			Relevance	No concerns about relevance[a]	
			Adequacy	No concerns about adequacy[a]	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
		a third expressed doubts and scepticism towards it. Some ‘doubters’ tended to prioritise symptoms (especially daytime sleepiness), and clinical signs (particularly obesity), implicitly or explicitly criticising the exclusion of these factors from the definition of OSA while relying on a specific image of the OSA patient as sleepy and obese. Other patients also disapproved of the diagnostic procedures and technology by suggesting that ‘laboratory sleep’ is not an accurate indicator of their quality of sleep at home. Reasons for seeking medical care - the primary reasons were due to input from spouse/partner, another family member, or friend, the participant’s own concern about particular symptoms and/or falling asleep while driving. Small numbers also reported seeking medical attention due to having a comorbidity, falling asleep at work, having a car accident due to EDS, being required by an employer, and seeing a sleep study advertisement.			

(a) Risk of bias was assessed using the CERQual checklist.

Table 8: Summary of evidence – Factors influencing partners' support

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
4 studies (88 people) Elfstrom 2012[13] Henry 2013[20] Stalkrantz 2012[47] Luyster 2016[32]	Semi-structured interviews	Studies found following areas very important in influencing partners' support: **Decisive situations influencing support negatively** - 5 categories of decisive situations influencing support negatively, as described by partners, were identified: adverse effects, limited effect, practical and physiological problems, limited presence and initiation routines perceived as inappropriate. **Decisive situations influencing support positively**-4 categories of decisive situations influencing support positively, as described by partners, were identified: Well-functioning treatment, improvements, high motivation and support from others **Managing of decisive situations**-4 categories of managing decisive situations that influenced the partners' support were identified: letting the patient handle the treatment himself/herself; handling of treatment together; or taking over handling of the treatment from the patient. The same partner used different types of behaviours in different situations if needed **Iconic cultural status of snoring**- For male patients in particular, the popular culture, comical representations of snoring in the popular culture made it difficult, and embarrassing, for them to talk about it seriously, and because of this perception, wives often struggled to push their partner to accept that their style of snoring was not normal.	Limitations	No concerns about methodological limitations[a]	High
			Coherence	No concerns about coherence[a]	
			Relevance	No concerns about relevance[a]	
			Adequacy	No concerns about adequacy[a]	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
		Snoring in women- For women whose snoring might indicate apnoea, a different kind of danger became apparent, that “considerate” male spouses could feel compelled to downplay or underreport the symptom, as it’s not considered something that women are supposed to do. **Social adjustment**-, Social adjustment’ included two categories that revealed different reactions to adjustments required by their partners’ symptoms. The first category ‘limited circumstances’ describes a feeling of lack of control, i.e. social adjustments. This could mean that they experienced limited time for their daily activities, e.g. on those days that their partner was tired, they received less help at home. The spouses also felt that the time for their own activities was decreased. The second category, ‘same circumstances’, conversely describes how the spouses were able to see the social adjustments as less of an issue of lack of control and more as a challenging circumstance requiring compromise. **Sacrificing-** Sacrificing was one way of managing everyday life for the spouses family and missed the support from their partners in getting help with everyday chores. The sacrifices the spouses did were connected with their partner’s tiredness and its consequences, but even their own tiredness led to their not having as much energy as earlier. **Controlling**- Controlling was another way of managing the life situation. The spouses felt they needed to have control, in everyday life, as well as during the night, in relation to their partner’s OSAS. Control was their own choice, but was perceived as a necessity in relation to the worry and anxiety they felt about their partner’s OSAS symptoms.			

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
		Changing- Changing was also a way of managing the everyday life. To make do different types of changes could help both the spouses, as well as their partners. The spouses expressed both fear and anxiety about the future, both concerning their own and their partner's health. **Understanding**- Understanding meant that even how hard it was for the spouses in their everyday life, it was important to have an Understanding for their partners OSAHS, as a way of managing the situation. Despite the anger over not being able to sleep properly and tiredness during the day, the spouses still described feelings of empathy as they felt sorry for their partner, because it was not his/her fault to suffer from OSAS. 'It must be dead tough'.			

(a) Risk of bias was assessed using the CERQual checklist.

1.5 Economic evidence

The committee agreed that health economic studies would not be relevant to this review question, and so health economic evidence relating to this question was not sought.

1.6 The committee's discussion of the evidence

1.6.1 Interpreting the evidence

1.6.1.1 The outcomes that matter most

The committee reviewed the evidence on what information and support do people and their families or carers need. Themes of interest, as stated in the protocol, were: advice on lifestyle, advice on driving and occupation, advice on treatment. Additional themes identified by the review were: type and format of the information, communication between patients and healthcare professionals, experiences of CPAP use, factors influencing behaviour change, factors influencing partners' support.

1.6.1.2 The quality of the evidence

The committee noted that majority of the evidence was from the point of view of people suffering from obstructive sleep apnoea and their partners and there was little health professional input identified in the studies.

The quality of evidence was high. There were no concerns about methodological limitations and no concerns regarding coherence, relevance and adequacy.

No evidence was available for people with OHS and COPD-OSAHS overlap syndrome.

1.6.1.3 Findings identified in the evidence synthesis

OSAHS

There was evidence from 25 studies in adult patients with OSAHS.

There was some evidence on type/format of information, importance of support groups, facilitators and barriers to CPAP use, communication between patients and healthcare professionals, factors influencing behaviour change, factors influencing seeking treatment and factors influencing partners support.

The committee discussed that providing appropriate information for people with OSAHS, OHS and COPD-OSAHS overlap syndrome is essential to help them understand their condition and access support and treatment. Attendance for sleep investigations, such as respiratory polygraphy, is likely to be higher if patients understand why these are being performed and what they entail. The committee agreed that information about all aspects of treatment is likely to increase uptake and therefore effectiveness.

The committee used evidence from this review, their interaction with their patient networks and experiences of the lay members to inform their recommendations on what information should be given to the patients.

The committee agreed that there are two related areas that this information should address: information to inform the patient's understanding of the condition, and information to help the patient make informed decisions about their care. The committee discussed that currently the information provided to patients is not always adequate to inform understanding of the condition and decision-making.

The evidence showed that people were found to be encouraged by friendly greeting, warm and positive clarification of the reason for a visit by the healthcare professional. People also expressed that at the beginning of the consultation understanding, but at the same time a committed and informative response from the healthcare personnel, was essential to empower the patients to be active and elicit their own perspective of OSAHS and CPAP.

The evidence identified that lack of awareness about the underlying causes of sleepiness, lack of knowledge about the availability of treatment services for OSAHS, attitudes towards their personal health and fear of not wanting to believe that something is physically wrong, or being apprehensive about finding out about further or more serious health conditions were key factors influencing patients' decision in seeking for treatment.

The evidence showed that patients wanted to have more information when receiving the diagnosis for the first time, including an explanation of the implications of having OSA diagnosis, the risks of not adhering to therapy, and how to use the CPAP device. Patients preferred more information about outcomes than the pathophysiology of the disease. However the committee agreed that it was helpful to provide information on pathophysiology, as it would help patients better understand the condition and how treatment could improve the condition. The evidence showed that even though most patients were aware that OSAHS and obesity could lead to medical problems such as heart disease, they were not always aware of risks associated with OSAHS. The evidence showed that even though most patients were aware of negative consequences of obesity and sleep apnoea they were actively ignoring such risks.

Based on the evidence and their experience the committee agreed that personalised information should be given to patients on: OSAHS, its causes/risk factors, symptoms, diagnosis including information on sleep studies, importance of treating OSAHS, treatment options, why treatment is the best option for the patients, impact of the condition on their daily lives and any long term effects of the condition, impact on driving and occupational risk, lifestyle changes and other sources of patient support . The committee from their experience highlighted the importance of providing advice on lifestyle changes such as losing excess weight, or cutting down on alcohol, that could help control symptoms/manage the condition.

The evidence showed that patients and partners suggested different format options and important components that would be valuable in developing a programme to help first-time CPAP users feel comfortable using CPAP. Small group sessions led by a respiratory therapist and/or a current CPAP user or an online video were identified by patients as optimal formats for providing the programme. Having an opportunity to ask questions and having a hands-on demonstration for setting up the machine and becoming familiar with different mask options were emphasised as important components of the programme that could help prepare new users. The evidence showed that patients preferred brochures and videotapes using fewer polysyllabic words and more personal communication. Some of the words were too difficult to understand and lacked the positive tone. The complexity of the words removed the emotion needed to deliver a clear message, and patients suggested more personal communication was needed to explain the treatments.The committee noted that some patients prefer more visual information such as brochures and short information films, but agreed that patients have varied preference and hence did not want to specify the format to provide information. The committee acknowledged that it is very important not only what type and format of information is presented to the patients but also the way it is presented.

The evidence showed that easy manageable routines and established habits of using CPAP, patients' high motivation of using CPAP and patients' understanding of risk of apnoeas and secondary diseases played an important role in partners support. Despite the anger over not being able to sleep properly and tiredness during the day, the spouses still described feelings of empathy as they felt sorry for their partner, because it was not his/her fault to suffer from OSAHS. The committee highlighted that the lack of evidence regarding issues such as difficulty for sleep apnoea patients in finding a partner, however the committee did not consider this to be a priority for research recommendation.

The committee agreed that information regarding OSAHS and driving should be provided to patients. The evidence showed that the main factors influencing treatment for drivers were lack of awareness about underlying causes of sleepiness, potential risks of sleepy driving and attitudes towards their personal health. The committee highlighted the importance of following guidance by DVLA on “Excessive Sleepiness” for driving in people with sleep apnoea.[12] (see Evidence report L for discussion of DVLA guidance for drivers with excessive sleepiness). The committee also discussed that untreated obstructive sleep apnoea could negatively impact work performance and productivity and this is particularly important in people involved in safety or vigilance critical duties, such operating machinery, driving, performing surgery or caring for vulnerable children or adults. The evidence review identified suggestions made by patients such as: support programmes for first time CPAP users, peer support and feedback from other patients. The committee discussed that patient support groups could be helpful for patients and their carers/family members, also in raising awareness of the condition.

The committee noted useful websites, such as the Sleep Apnoea Trust Association which has a range of patient information, including leaflets regarding CPAP (What is OSA, Snoring and OSA, Living with your CPAP, Dealing with CPAP claustrophobia and panic attacks, Sleep Apnoea and Hospital Admissions, plus on their website detailed DVLA Guidance for UK drivers with OSA); also the British Lung Foundation has generic information. CPAP manufacturers may provide educational information on their websites also relating to CPAP use and upkeep.

The evidence showed certain areas as very important in influencing partners’ support. Problems with mask such as mask leakage caused noise and necessary actions to refit the mask caused awakenings at night and impaired sleep for both patient and partner. Partners described that a limited initial treatment effect with unmitigated symptoms led to disappointment and reduced faith in the treatment. Psychological problems such as inhibited closeness, feelings of shame and practical problems were also mentioned as important factors negatively influencing partners’ support.

The committee agreed that appropriate information should be given to people about CPAP, including: how to operate it and clean the kit, who to contact for replacement parts and machine issues (ideally two points of contact: one for replacement parts and another for clinical contact), different mask options and how to deal with problems with masks, the importance of persevering with using CPAP, training provisions at the time of CPAP, taking a break from using CPAP for a few (e.g. 3) nights, how to deal with problems associated with CPAP use and how often to expect follow up appointments.

The committee agreed that patients should be provided with information on travelling with CPAP or non-invasive ventilation: advice for travelling by flights/cruise ships/bus, and other considerations about co-existing conditions and hygiene when travelling abroad. For example: having a medical letter explaining that a patient is a CPAP/non-invasive ventilationuser is useful for airport security, keeping CPAP/non-invasive ventilation in hand luggage, liaising with the airline/cruise company/bus company if a plug socket is needed on a journey for CPAP/non-invasive ventilation use, taking appropriate plugs for other countries and extension cables. If a patient has oxygen also, this will need to be arranged as per oxygen guidelines.[34]

The committee agreed that people using CPAP or non-invasive ventilation should be advised that these are aerosol generating procedures, and they should take appropriate precautions to reduce the risk of airborne infection such as COVID-19, using equipment in a well-ventilated room and using equipment away from other family members if possible. For more information, see the UK government guidance on COVID-19: infection prevention and control.[39]

The committee noted that in current practice, information provision regarding CPAP is varied, with some centres offering one to one CPAP set up sessions, others offering group CPAP set up sessions, plus various support leaflets and access to online help.

The committee agreed that patients using a custom-made mandibular advancement splint (MAS) should be provided with information on short term effects such as excessive salivation, changes in bite, mild discomfort and long term effects such as changes to dental occlusion. The committee agreed that information should also be provided on on adjusting the appliance to ensure maximum clinical therapeutic benefit. This should be optimised prior to a repeat overnight sleep study to assess progress. Information is also needed on how to clean the MAS, when to replace it, and the importance of regular follow-up visits with the dentist to ensure maintenance of good oral health.

OHS

No evidence was available for people with OHS. The committee agreed that the recommendations for OSAHS could apply to people with OHS as the principles are the same.

COPD-OSAHS overlap syndrome

No evidence was available for people with COPD-OSAHS overlap syndrome. The committee agreed that the recommendations for OSAHS could apply to people with with COPD-OSAHS overlap syndrome as the principles are the same.

1.6.1.4 Cost effectiveness and resource use

Cost effectiveness evidence was not sought as this was a qualitative review. The recommendations provide guidance regarding the content of information and support required for people with OSAHS, OHS, COPD-OSAHS overlap syndrome. This is in line with the general principles of provision of information already established in the existing NICE Patient experience guideline (CG138).

The recommendations were not considered likely to have a substantial resource impact over and above CG138.

If good patient information improves adherence to treatment then it could improve the efficiency of treatment.

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Appendices

Appendix A: Review protocols

Table 9: Review protocol: Information and support

Field	Content
PROSPERO registration number	Not registered.
Review title	Information and support
Review question	What information and support do people and their families or carers need (for example, advice on lifestyle, driving and occupation, and their treatment)?
Objective	To determine what information and support do people and their families or carers need (for example, advice on lifestyle, driving and occupation, and their treatment)
Searches	The following databases (from inception) will be searched: • Embase • MEDLINE • CINAHL • PsycINFO Searches will be restricted by: • English language studies The searches may be re-run 6 weeks before the final committee meeting and further studies retrieved for inclusion if relevant. The full search strategies will be published in the final review.
Condition or domain being studied	Obstructive sleep apnoea/hypopnoea syndrome is the most common form of sleep disordered breathing. The guideline will also cover obesity hypoventilation syndrome and COPD-OSAHS overlap syndrome (the coexistence of obstructive sleep apnoea/hypopnoea syndrome and chronic obstructive pulmonary disease).
Population	People with OSAHS/OHS/COPD-OSAHS overlap syndrome, their family/carers and healthcare professionals involved in their care Evidence will be stratified by: • OSAHS vs OHS vs COPD-OSAHS overlap syndrome • Investigation, diagnosis and assessment vs long term treatment
Intervention/Exposure/Test	Views, opinions and experiences relating to information and support.
Comparator/Reference standard/Confounding factors	NA
Types of study to be included	Qualitative studies using any appropriate methodology (e.g. semi-structured interviews or focus groups with ethnography or grounded theory based

	analysis) and systematic reviews of qualitative studies will be considered for inclusion.
Other exclusion criteria	Non-English language studies. Conference abstracts will be excluded as it is expected there will be sufficient full text published studies available. Only including studies in OECD countries
Context	NA
Primary outcomes (critical outcomes)	Outcomes will be dictated by the themes included in the studies in the review, however areas that may be of particular interest include: • Advice on lifestyle • Advice on driving and occupation • Advice on treatment
Secondary outcomes (important outcomes)	NA
Data extraction (selection and coding)	EndNote will be used for reference management, sifting, citations and bibliographies. All references identified by the searches and from other sources will be screened for inclusion. 10% of the abstracts will be reviewed by two reviewers, with any disagreements resolved by discussion or, if necessary, a third independent reviewer. The full text of potentially eligible studies will be retrieved and will be assessed in line with the criteria outlined above. A standardised form will be used to extract data from studies (see Developing NICE guidelines: the manual section 6.4).
Risk of bias (quality) assessment	Risk of bias will be assessed using the appropriate checklist as described in Developing NICE guidelines: the manual. The methodological quality of each study will be assessed using the CASP qualitative checklist 10% of all evidence reviews are quality assured by a senior research fellow. This includes checking: • papers were included /excluded appropriately • a sample of the data extractions • correct methods are used to synthesise data • a sample of the risk of bias assessments Disagreements between the review authors over the risk of bias in particular studies will be resolved by discussion, with involvement of a third review author where necessary.
Strategy for data synthesis	The synthesis of qualitative data will follow a thematic analysis approach. Information will be synthesised into main review findings. Results will be presented in a detailed narrative and in table format with summary statements of main review findings. The GRADE-CERQual approach will be used for quality assessment of synthesised qualitative evidence brought together in thematic analysis.

	Additional qualitative studies will be added to the review until themes within the analysis become saturated; i.e. studies will only be included if they contribute towards the development of existing themes or to the development of new themes.	
Analysis of sub-groups	NA	
Type and method of review	☐	Intervention
	☐	Diagnostic
	☐	Prognostic
	☒	Qualitative
	☐	Epidemiologic
	☐	Service Delivery
	☐	Other (please specify)
Language	English	
Country	England	
Anticipated or actual start date	NA	
Anticipated completion date	NA	
Named contact	5a. Named contact National Guideline Centre 5b Named contact e-mail SleepApnoHypo@nice.org.uk 5e Organisational affiliation of the review National Institute for Health and Care Excellence (NICE) and the National Guideline Centre	
Review team members	From the National Guideline Centre: Carlos Sharpin, Guideline lead Sharangini Rajesh, Senior systematic reviewer Audrius Stonkus, Systematic reviewer Emtiyaz Chowdhury (until January 2020), Health economist David Wonderling, Head of health economics Agnes Cuyas, Information specialist (till December 2019) Jill Cobb, Information specialist	
Funding sources/sponsor	This systematic review is being completed by the National Guideline Centre which receives funding from NICE.	
Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must	

	declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10098
Other registration details	NA – not registered.
Reference/URL for published protocol	NA – not registered.
Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.
Keywords	-
Details of existing review of same topic by same authors	NA
Additional information	-
Details of final publication	www.nice.org.uk

Appendix B: Literature search strategies

Sleep apnoea search strategy 5 – information and support

This literature search strategy was used for the following review;

- What information and support do people and their families or carers need (for example, advice on lifestyle, driving and occupation, and their treatment)?

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual.[35]

For more information, please see the Methods Report published as part of the accompanying documents for this guideline.

B.1 Clinical search literature search strategy

Searches for patient views were run in Medline (OVID), Embase (OVID), CINAHL, Current Nursing and Allied Health Literature (EBSCO) and PsycINFO (ProQuest). Search filters were applied to the search where appropriate.

Table 10: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (OVID)	1946 – 6 July 2020	Exclusions Qualitative studies
Embase (OVID)	1974 – 6 July 2020	Exclusions Qualitative studies
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 6 July 2020	Exclusions Qualitative studies
PsycINFO (ProQuest)	Inception – 6 July 2020	Exclusions

Medline (Ovid) search terms

1.	exp Sleep Apnea Syndromes/
2.	(sleep* adj4 (apn?ea* or hypopn?ea*)).ti,ab.
3.	(sleep* adj4 disorder* adj4 breath*).ti,ab.
4.	(OSAHS or OSA or OSAS).ti,ab.
5.	(obes* adj3 hypoventil*).ti,ab.
6.	pickwick*.ti,ab.
7.	or/1-6
8.	limit 7 to English language
9.	letter/
10.	editorial/
11.	news/
12.	exp historical article/
13.	Anecdotes as Topic/
14.	comment/
15.	case report/
16.	(letter or comment*).ti.
17.	or/9-16
18.	randomized controlled trial/ or random*.ti,ab.
19.	17 not 18
20.	animals/ not humans/

21.	exp Animals, Laboratory/
22.	exp Animal Experimentation/
23.	exp Models, Animal/
24.	exp Rodentia/
25.	(rat or rats or mouse or mice).ti.
26.	or/19-25
27.	8 not 26
28.	Patients/ or Inpatients/ or Outpatients/
29.	Caregivers/ or exp Family/ or exp Parents/ or exp Legal-Guardians/
30.	(patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient*).ti,ab.
31.	or/28-30
32.	Patient Education Handout/ or exp Information-Services/ or Publications/ or Books/ or Pamphlets/ or Counseling/ or Directive-Counseling/
33.	31 and 32
34.	(patient* adj3 (education or educate or educating or literature or leaflet* or booklet* or pamphlet* or information*)).ti,ab.
35.	Patient Education as Topic/
36.	Consumer Health Information/
37.	(information* adj3 (need* or requirement* or support* or seek* or access* or disseminat* or barrier*)).ti,ab.
38.	((educat* or learn* or support*) adj3 (service* or literature or leaflet* or booklet* or pamphlet* or information* or manual* or brochure* or publication* or handout* or material* or program*)).ti,ab.
39.	(discharge* adj3 (information* or advice or support*)).ti,ab.
40.	or/34-39
41.	exp Consumer Behavior/ or Personal-Satisfaction/ or exp Patient-Acceptance-Of-Health-Care/
42.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform*)).ti,ab.
43.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (knowledge or awareness or misconception* or understanding or misunderstanding)).ti,ab.
44.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (experience or experiences or opinion* or concern* or belief* or feeling* or idea* or satisfaction or anxiet* or fear* or acceptance or denial or stigma* or label* or behaviour* or behavior*)).ti,ab.
45.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (need* or requirement* or support* or communication* or involve*)).ti,ab.
46.	or/41-45
47.	33 or 40 or 46
48.	27 and 47
49.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp "Surveys and Questionnaires"/ or Health care surveys/
50.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
51.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or

	grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
52.	or/49-51
53.	48 and 52

Embase (Ovid) search terms

1.	exp Sleep Disordered Breathing/
2.	(sleep* adj4 (apn?ea* or hypopn?ea*)).ti,ab.
3.	(sleep* adj4 disorder* adj4 breath*).ti,ab.
4.	(OSAHS or OSA or OSAS).ti,ab.
5.	(obes* adj3 hypoventil*).ti,ab.
6.	pickwick*.ti,ab.
7.	or/1-6
8.	limit 7 to English language
9.	letter.pt. or letter/
10.	note.pt.
11.	editorial.pt.
12.	case report/ or case study/
13.	(letter or comment*).ti.
14.	or/9-13
15.	randomized controlled trial/ or random*.ti,ab.
16.	14 not 15
17.	animal/ not human/
18.	nonhuman/
19.	exp Animal Experiment/
20.	exp Experimental Animal/
21.	animal model/
22.	exp Rodent/
23.	(rat or rats or mouse or mice).ti.
24.	or/16-23
25.	8 not 24
26.	*patient/ or *hospital patient/ or *outpatient/
27.	*caregiver/ or *family/ or adult child/ or family relation/ or grandparent/ or military family/ or nuclear family/ or single-parent family/ or *parent/ or father/ or mother/ or single parent/ or legal guardian/
28.	(patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient*).ti,ab.
29.	or/26-28
30.	information service/ or documentation/ or publication/ or book/ or counseling/ or directive counseling/
31.	29 and 30
32.	(patient* adj3 (education or educate or educating or literature or leaflet* or booklet* or pamphlet* or information*)).ti,ab.
33.	patient education/
34.	consumer health information/

35.	(information* adj3 (need* or requirement* or support* or seek* or access* or disseminat* or barrier*)).ti,ab.
36.	((educat* or learn* or support*) adj3 (service* or literature or leaflet* or booklet* or pamphlet* or information* or manual* or brochure* or publication* or handout* or material* or program*)).ti,ab.
37.	(discharge* adj3 (information* or advice or support*)).ti,ab.
38.	or/32-37
39.	*consumer attitude/ or *satisfaction/ or patient attitude/ or patient compliance/ or patient dropout/ or patient participation/ or patient preference/ or patient satisfaction/
40.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform*)).ti,ab.
41.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (knowledge or awareness or misconception* or understanding or misunderstanding)).ti,ab.
42.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (experience or experiences or opinion* or concern* or belief* or feeling* or idea* or satisfaction or anxiet* or fear* or acceptance or denial or stigma* or label* or behaviour* or behavior*)).ti,ab.
43.	((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) adj3 (need* or requirement* or support* or communication* or involve*)).ti,ab.
44.	or/39-43
45.	31 or 38 or 44
46.	25 and 45
47.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
48.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
49.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
50.	or/47-49
51.	46 and 50

CINAHL (EBSCO) search terms

S1.	(MH "Sleep Apnea Syndromes+")
S2.	TI (sleep* n4 (apn?ea* or hypopn?ea*))
S3.	AB (sleep* n4 (apn?ea* or hypopn?ea*))
S4.	TI (sleep* n4 disorder* n4 breath*)
S5.	AB (sleep* n4 disorder* n4 breath*)
S6.	TI (OSAHS or OSA or OSAS)
S7.	AB (OSAHS or OSA or OSAS)
S8.	TI (obes* n3 hypoventil*)
S9.	AB (obes* n3 hypoventil*)
S10.	TI (pickwick*)
S11.	AB (pickwick*)
S12.	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11

S13.	PT anecdote or PT audiovisual or PT bibliography or PT biography or PT book or PT book review or PT brief item or PT cartoon or PT commentary or PT computer program or PT editorial or PT games or PT glossary or PT historical material or PT interview or PT letter or PT listservs or PT masters thesis or PT obituary or PT pamphlet or PT pamphlet chapter or PT pictorial or PT poetry or PT proceedings or PT "questions and answers" or PT response or PT software or PT teaching materials or PT website
S14.	S12 NOT S13
S15.	(MH "Patients") OR (MH "Inpatients") OR (MH "Outpatients")
S16.	(MH "Caregivers") OR (MH "Family+") OR (MH "Parents+") OR (MH "Guardianship, Legal+")
S17.	TI (patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient*)
S18.	AB (patient* or carer* or caregiver* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or next of kin or significant other* or partner* or guardian* or inpatient* or outpatient*)
S19.	S15 OR S16 OR S17 OR S18
S20.	(MH "Information Services+") OR (MH "Books") OR (MH "Pamphlets") OR (MH "Counseling")
S21.	S19 AND S20
S22.	TI (patient* n3 (education or educate or educating or literature or leaflet* or booklet* or pamphlet* or information*))
S23.	AB (patient* n3 (education or educate or educating or literature or leaflet* or booklet* or pamphlet* or information*))
S24.	(MH "Patient Education")
S25.	(MH "Consumer Health Information")
S26.	TI (information* n3 (need* or requirement* or support* or seek* or access* or disseminat* or barrier*))
S27.	AB (information* n3 (need* or requirement* or support* or seek* or access* or disseminat* or barrier*))
S28.	TI ((educat* or learn* or support*) n3 (service* or literature or leaflet* or booklet* or pamphlet* or information* or manual* or brochure* or publication* or handout* or material* or program*))
S29.	AB ((educat* or learn* or support*) n3 (service* or literature or leaflet* or booklet* or pamphlet* or information* or manual* or brochure* or publication* or handout* or material* or program*))
S30.	TI (discharge* n3 (information* or advice or support*))
S31.	AB (discharge* n3 (information* or advice or support*))
S32.	S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31
S33.	(MH "Consumer Attitudes") OR (MH "Personal Satisfaction") OR (MH "Patient Attitudes") OR (MH "Patient Compliance") OR (MH "Patient Dropouts") OR (MH "Patient Preference") OR (MH "Patient Satisfaction")
S34.	TI ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform*))
S35.	AB ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform*))
S36.	TI ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (knowledge or awareness or misconception* or understanding or misunderstanding))

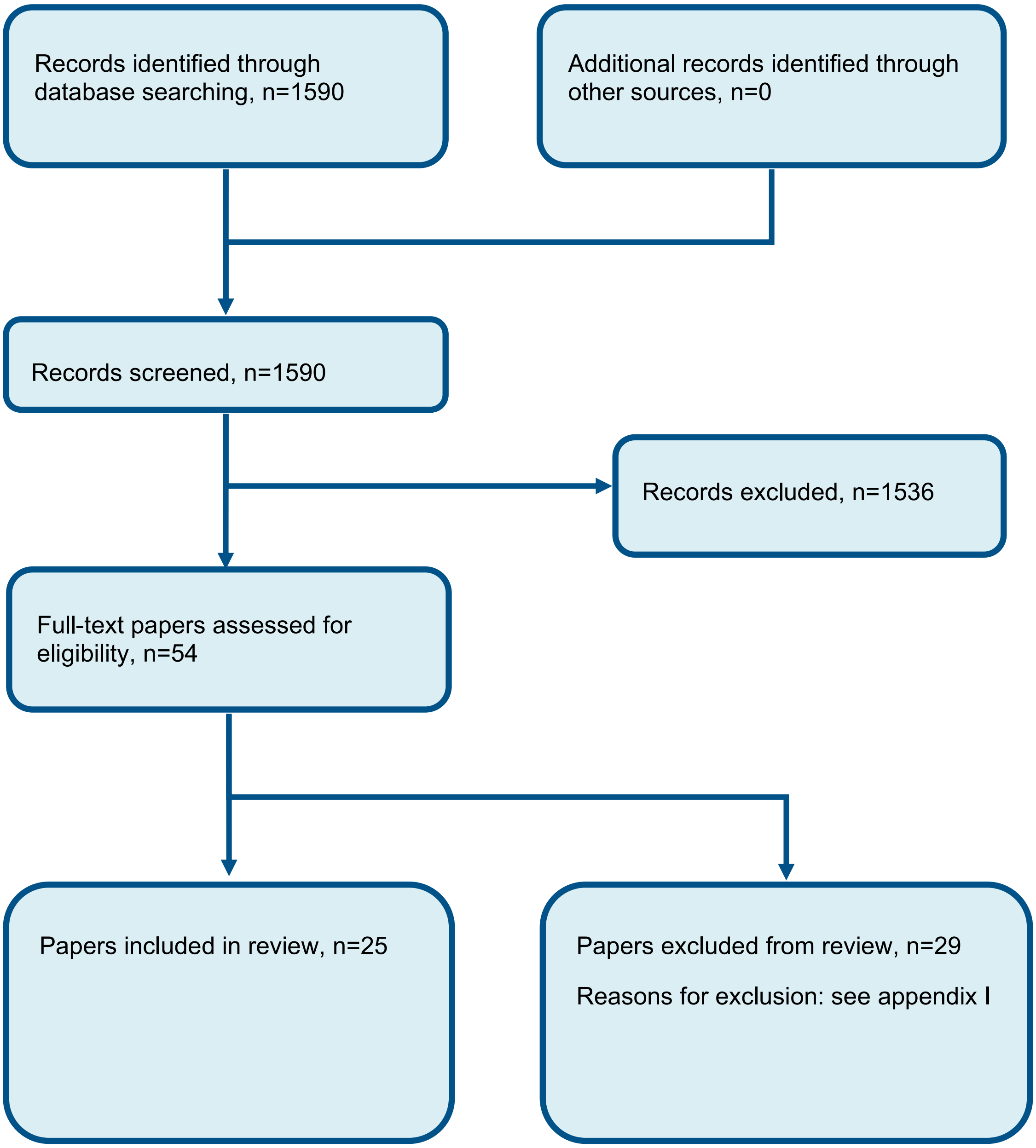
S37.	AB ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (knowledge or awareness or misconception* or understanding or misunderstanding))
S38.	TI ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (experience or experiences or opinion* or concern* or belief* or feeling* or idea* or satisfaction or anxiet* or fear* or acceptance or denial or stigma* or label* or behaviour* or behavior*))
S39.	AB ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (experience or experiences or opinion* or concern* or belief* or feeling* or idea* or satisfaction or anxiet* or fear* or acceptance or denial or stigma* or label* or behaviour* or behavior*))
S40.	TI ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (need* or requirement* or support* or communication* or involve*))
S41.	AB ((patient* or user* or carer* or famil* or parent* or father* or mother* or spouse* or wife or wives or husband* or significant other* or partner*) n3 (need* or requirement* or support* or communication* or involve*))
S42.	S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41
S43.	S21 OR S32 OR S42
S44.	S14 AND S43
S45.	(MH "Qualitative Studies+")
S46.	(MH "Qualitative Validity+")
S47.	(MH "Interviews+") OR (MH "Focus Groups") OR (MH "Surveys") OR (MH "Questionnaires+")
S48.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*)
S49.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*)
S50.	S45 OR S46 OR S47 OR S48 OR S49
S51.	S44 AND S50

PsycINFO (ProQuest) search terms

1.	(((MAINSUBJECT.EXACT.EXPLODE("Sleep Apnea") OR ti,ab(sleep* NEAR/4 (apn?ea* OR hypopn?ea*)) OR ti,ab(sleep* NEAR/4 disorder* NEAR/4 breath*) OR ti,ab(OSAHS OR OSA OR OSAS) OR ti,ab(obes* NEAR/3 hypoventil*) OR ti,ab(pickwick*)) AND (MAINSUBJECT.EXACT("Patients") OR MAINSUBJECT.EXACT("Outpatients") OR MAINSUBJECT.EXACT.EXPLODE("Parents") OR MAINSUBJECT.EXACT("Caregivers") OR MAINSUBJECT.EXACT.EXPLODE("Family") OR MAINSUBJECT.EXACT("Guardianship"))) NOT (su.exact.explode("rodents") OR su.exact.explode("mice") OR (su.exact("animals") NOT (su.exact("human males") OR su.exact("human females"))) OR ti(rat OR rats OR mouse OR mice))) AND la.exact("English")

Appendix C: Clinical evidence selection

Figure 1: Flow chart of clinical study selection for the review of Information and support



Appendix D: Clinical evidence tables

Study	Brostrom 2010[8]
Aim	To explore the experiences of adherence to CPAP treatment in patients with OSAHS.
Population	23 patients with OSAHS
Setting	Participants were recruited from two CPAP clinics (one university hospital and one county hospital)
Study design	Unstructured interviews of primary care physicians
Methods and analysis	Qualitative content analysis (QCA)
Findings	Putative facilitators of adherence to CPAP treatment – described by the patients were a desire to avoid symptoms of OSAHS, knowledge about the risk of medical consequences, fear of negative social consequences and disturbing the sleep of significant others. The patients also described a positive attitude to CPAP treatment, trust in healthcare personnel, a sense of engagement from the next of kin, and an experience of physical involvement from the CPAP treatment as a positive facilitators.
	Putative barriers for adherence to CPAP treatment – Patients described experiences of practical problems, negative psychological effects of equipment, and negative attitudes to CPAP treatment as putative barriers to their adherence. Further, they described experiences of side-effects of the CPAP treatment as well as insufficient support from healthcare personnel and their next of kin Barriers.
Limitations and applicability of evidence	No notable limitations

Study	Brostrom 2017[7]
Aim	To describe facilitators and barriers from a patient perspective in communications between patients with obstructive sleep apnoea syndrome and healthcare personnel during the first meeting when continuous positive airway pressure is initiated.
Population	25 patients with obstructive sleep apnoea syndrome took place after their initial visit at four continuous positive airway pressure clinics.

Study	Brostrom 2017[7]
Setting	four continuous positive airway pressure clinics
Study design	Interviews with 25 patients with obstructive sleep apnoea syndrome took place after their initial visit at four continuous positive airway pressure clinics
Methods and analysis	A deductive analysis based on The 4 Habits Model (i.e. emphasise the importance of investing in the beginning of the consultation, elicit the patient’s perspective, demonstrate empathy and invest in the end of the consultation) was conducted.
Findings	Confidence building – Structure building, information transfer, commitment.
	Confidence hindering – organisational insufficiency, stress behaviour, interaction deficit aspects of communication at the beginning of the consultation between patients with OSAS and healthcare personnel
	Motivating - situational insight, knowledge transfer, practical training
	Demotivating - expectations, dominance and power asymmetry barriers
	Hope building - awareness, sensitivity, demonstration of understanding
	Hope hindering – Incomprehension, uncommitted, unprepared
	Agreement – confirmation, responsibilities, comprehensive information
	Disagreement – structural obscurity, irresponsibility, absent-minded
Limitations and applicability of evidence	Used a sample from four CPAP clinics. Other clinics may have other routines during the initial visit (e.g. longer time or group-based information) that might affect communication. However, a strategically selected and clinically relevant sample from different areas of Sweden increased the possibility of achieving maximal

Study	Dickerson 2006[10]
Aim	Study examined help-seeking experiences in support groups of individuals with sleep apnoea who use CPAP devices
Population	17 individuals with sleep apnoea who use CPAP for treatment and attend a support group.
Setting	an urban medical centre and a rural hospital shared data collected from 17 individuals with sleep apnoea. two institutions, A general hospital in an urban area and a rural hospital. The general hospital had a sleep centre where sleep studies were conducted and sleep apnoea was diagnosed. The urban support group was started by a clinical nurse specialist (CNS) in May 2001 to offer education and guidance to meet the needs of individuals with sleep apnoea who use CPAP.
Study design	Support groups

Study	Dickerson 2006[10]
Methods and analysis	The methodology for this study was Heideggerian hermeneutics (Hiedegger, 1927/1962), a phenomenological approach whereby researchers uncover the common meanings of individuals' experiences through analysis of semi-structured interviews.
Findings	Four related themes emerged including (a) becoming motivated to persist with help from the group, (b) accommodating to the device, (c) listening and telling stories to gain practical knowledge, and (d) implementing a support group as a caring community
	(a) Becoming motivated to persist with help from the group - Motivation to persist through initial and recurring frustration with help from the support group was the first theme. Informants told stories of dealing with disruptive symptoms of sleep apnoea including frightening experiences such as falling asleep while driving. They also told of the "constant fatigue," "feeling the need to sleep," and "awakening exhausted in the morning." These symptoms triggered the need for seeking a diagnosis by polysomnography.
	(b) Accommodating to the device - Experts relate accommodating to the device. Informants that had been using CPAP for a longer time learned how to accommodate the device into their lifestyle. The word accommodation was used instead of compliance or adherence because it implied the give and take required to integrate CPAP use into their lives and to become motivated to persist throughout the adjustment period. They became motivated to give up being able to just go to sleep, hearing the night sounds, and for some, sleeping with their partners.
	(c) Listening and telling stories to gain practical knowledge - Listening and telling stories to gain practical knowledge was the focus of theme three. The informants said that listening to others' stories helped with continuing difficulties by providing ideas and practical advice. Many had little instruction from the homecare companies on machine maintenance. One admitted he felt like he "fell through the cracks" of the healthcare providers and had many unmet needs.
	(d) Implementing a support group as a caring community - Support groups are communities that provide information and encouragement to persevere. One man said, "It's a pep talk. After the first meeting I went right home, put the machine on, and had a good night's sleep." Another described the group as a "gathering of common folks with common experiences and a very uncommon resolve."
Limitations and applicability of evidence	No notable limitations

Study	Dickerson 2013[11]
Aim	Development and usability testing of a self-management intervention to promote CPAP adherence
Population	Ten participants with varying ages, race, education, and CPAP usage, found the intervention contained useful informat

Study	Dickerson 2013[11]
	ion to understand their diagnosis, to problem-solve, and monitor their progress. Mean age of 42.7 (13.7), 4 males and 6 females of which 30% were African American and 70 % white.
Setting	Not specified
Study design	Telephone interview using "talk-out-loud technique" to determine usability. The interviews transcripts were analysed thematically.
Methods and analysis	The initial steps in the Campbell (2000) Framework for complex intervention guided development of the intervention in book format. After sleep expert review and modification, CPAP users reviewed the format and content of the intervention and were interviewed by telephone using a "talk-out-loud technique" to determine usability. The interviews transcripts were analysed thematically.
Findings	Feedback on the intervention – General themes included: need for awareness of potential implications of untreated OSA; understanding diagnosis assists in communicating with providers and vendors; Help in problem solving CPAP mask issues; monitoring progress assisted in noticing symptom improvement; and patient stories helping realize you are not alone.
	Content revisited – revisions related to changing order of content such as putting the symptoms of sleep apnoea before the good news about CPAP treatment, making pictures larger, limiting the length of the patient stories, and altering the words “supine” and “prone” to improve readability.
	Content added – additional information was requested to clarify understanding of the sleep study, sleep stages and oxygen saturation levels. Content od adjusting the fit of the mask was suggested to supplement demonstrations by the vendor.
	Feedback on organization and process – several participants suggested that it would be beneficial to give the intervention book to patients when initially diagnosed with OSA before starting on CPAP.
	Suggestions for other patients – Participants suggested to others to get the CPAP machine as soon as possible, read about CPAP before getting it to be more prepared and to find resources to help with CPAP adjustments. Another reiterated comments from the intervention, such as, put the mask on before even going to bed at the beginning to get used to it and to focus thinking on positive outcomes which would make it easier to accept the mask.
Limitations and applicability of evidence	No notable limitations

Study	Elfstrom 2012[13]
Aim	The aim of this study was to explore and describe decisive situations affecting partners' support to patients with OSAHS and how the partners manage these situations during the initial phase of CPAP treatment.
Population	25 strategically selected partners of patients with CPAP treated OSAHS

Study	Elfstrom 2012[13]
Setting	CPAP clinic at the Swedish county hospital
Study design	A qualitative descriptive design using critical incident technique was used. A total of 542 decisive situations affecting partners' support and 222 situations describing managing were collected by means of interviews with 25 strategically selected partners of patients with CPAP treated OSAS.
Methods and analysis	The transcribed interviews were first read several times to obtain a sense of the whole. In the data reduction 2 researchers first individually marked and then together discussed incidents identified as critical to reach consensus. An incident either positive or negative was considered critical if it was related to the study aim. A total of 542 critical incidents and 222 situations describing how situations managed were identified. Saturation was reached after 20m interviews.
Findings	Decisive situations influencing support negatively – 5 categories of decisive situations influencing support negatively, as described by partners, were identified: adverse effects, limited effect, practical and physiological problems, limited presence and initiation routines perceived as inappropriate.
	Decisive situations influencing support positively. 4 categories of decisive situations influencing support positively, as described by partners, were identified: Well-functioning treatment, improvements, high motivation, and support from others.
	Managing of decisive situations – 3 different types of behaviour for managing decisive situations that influenced the partners' support were identified: letting the patient handle the treatment himself/herself; handling of treatment together; or taking over handling of the treatment from the patient. The same partner used different types of behaviours in different situations if needed.
Limitations and applicability of evidence	No notable limitations

Study	Firestone 2010[15]
Aim	To examine the attitudes of taxi drivers towards symptoms of obstructive sleep apnoea syndrome (OSAHS), and to determine whether these attitudes could influence their health and safety as a professional driver.
Population	Participants were 27 taxi drivers who had a high pre-test risk for obstructive sleep apnoea. Assignment to focus groups was based on self-identification as being Maori and Pacific peoples, New Zealand European, or non-Maori and non-Pacific.
Setting	The groups were conducted at the Research School of Public Health, Massey University (New Zealand), in an environment that offered a neutral context for drivers to interact freely and with anonymity from their company management. The focus groups were co-facilitated by one of the named authors (RF) and a qualified medical physician. Each group lasted two hours. Nominal group technique was employed to minimise influence and tangential discussion

Study	Firestone 2010[15]
Study design	Qualitative research based on 3 focus groups
Methods and analysis	Nominal group technique was employed to minimise influence and tangential discussion
Findings	Ignorance - Ignorance was defined as a lack of awareness about the underlying causes of sleepiness, and the potential risks of sleepy driving, and a lack of knowledge about the availability of treatment services for OSAS. It included both driver ignorance and ignorance among medical professionals. The following excerpts typify driver ignorance.
	Avoidance - The second sub-theme, avoidance, was defined as a conscious decision by drivers not to reveal health concerns to their GPs. The following discussion illustrates this.
	Personal fear - The third sub-theme was personal fear. This was characterised by drivers not wanting to believe that something is physically wrong, or being apprehensive about finding out about further or more serious health conditions that could compromise their ability to earn a living. A common element in this sub-theme was mistrust of other people's concerns about the driver's health.
Limitations and applicability of evidence	No notable limitations

Study	Fung 2017[17]
Aim	To explore older adults communication with their providers, preferences for communication, and views on communication attributes and decision aid characteristics, by conducting four focus groups.
Population	Patients were eligible if they were 65 years or older, had been diagnosed with OSA on a sleep study, and had not been told by a physician that they have dementia
Setting	We conducted four focus groups of patients from two health systems (Department of Veterans Affairs [VA] and academic) in Los Angeles in April and May 2014. Both health systems have comprehensive sleep centres and offer the most common SA treatments (i.e., PAP, oral appliances, surgery).
Study design	Focus groups, open ended questions
Methods and analysis	The Theory of Planned Behaviour (TPB; Aizen, 1985) served as the overarching framework for the overall research study, which aims to develop a patient decision aid related to OSA treatment. The research study began with the focus groups described in this paper. According to this framework, attitudes, subjective norms (e.g., referent beliefs about what behaviours others expect), and perceived behavioural control (e.g., perception of personal influences on the behaviour and perceived difficulties performing the behaviour)

Study	Fung 2017[17]
	influence intention to use SA therapy, which in turn affects adherence to therapy. Adherence affects health outcomes. This framework was used to develop the focus group discussion guide.
Findings	Description of Communication Between Patients and Health Care Providers - Communication about the causes of SA and the risks of living with SA ranged from very negative to very positive. Participant responses indicated a desire to have more information when receiving the diagnosis for the first time, including an explanation of the implications of having an SA diagnosis, the risks of not adhering to therapy, and how to use the PAP device.
	Participants’ Beliefs, Attitudes, and Preferences for Patient-Provider Communication and Decision Making - Some participants believed that they should be provided with more information about their diagnosis and treatment to make them more knowledgeable, which in turn could provide them with more power over their condition and make the decision-making process a joint effort.
	Participants’ Perspectives About Decision Aids - Participants provided a variety of perspectives about their level of interest in an SA decision aid. Most participants expressed interest in an SA decision aid. They felt that information provided about SA and treatment options to newly diagnosed patients could help patients communicate with providers about their disease and treatment options. However, a few participants felt that they could obtain information through existing sources on the Internet or that the sleep centre provider should already be providing the information without the use of a decision aid.
Limitations and applicability of evidence	No notable limitations

Study	Henry 2013[20]
Aim	To illuminate the significance of gender and partner-reporting in shaping the lay diagnosis, management, and treatment of obstructive sleep apnoea
Population	Patients (and partners) clinically diagnosed with sleep apnoea were recruited by a physician
Setting	Dallas metropolitan area, USA
Study design	In-depth, semi-structured interviews with both patients and partners (n = 24).
Methods and analysis	This cross-sectional, exploratory, mixed-methods study
Findings	Describing symptoms/ diagnosis – in 10/12 cases (83%), patients were unable to report first hand on the immediate experience of their behavioural symptoms. Except as these were described to them by spouses, children or even friends who had observed them sleep.

Study	Henry 2013[20]
	Spousal descriptions of nigh time behaviour were crucial to diagnosis, and became central to how patients understood both the nature and severity of the problem.
	Iconic cultural status of snoring, particularly for men, became evident in interviews. For male patients in particular, the popular culture, comical representations of snoring made it difficult, and embarrassing, for them to talk about it seriously.
	Snoring in women - For women whose snoring might indicate apnoea, a different kind of danger became apparent that “considerate” male spouses could feel compelled to downplay or underreport the symptom, as it’s not considered something that women are supposed to do.
	Daytime effects/impact of apnoea - What patients could do, and often did was come to understand their nigh time symptoms in terms of their daytime effects.
	Aetiology – When asked to what they attributed the cause of their apnoea respondents mostly characterized their problem as being one of weight, control of which would alleviate if not end their symptoms. “Weight “was mentioned as “the primary causes” of the problem for 50% of respondents; spouses were more likely to indicate weight as the main problem (58%) than patients (33%).
	Help seeking behaviour – Patients were asked about the difference in time between when they “first recognised the problem” and when they actually sought for help. The mean delay reported was by patients was 4.8 years (SD5.8).
	Perceptions of treatment – Interviews indicated that patients rapidly developed “love hate” relationship with their CPAP machine.
Limitations and applicability of evidence	Patients and spouses were interviewed after they sought medical advice from a sleep specialist, assessments of how explanatory models came to be historically constructed and contested were therefore limited to what patients and their partners could recall, thought this effect was somewhat mitigated by having two people to interview about each illness episode. All but 2 couples were interviewed shortly after patients began treatment with CPAP; It could be that reasons for dissatisfaction or partial adherence with CPAP change over time.

Study	Igelstrom 2012[23]
Aim	The purpose of this study was to explore aspects of engagement in physical activity in persons with obstructive sleep apnoea and overweight.
Population	Seven women and 8 men with obstructive sleep apnoea and obesity were interviewed
Setting	Sleep laboratory at the Department of Lung Medicine, Akademiska Sjukhuset in Uppsala, Sweden.
Study design	Interviews. Transcribed data were analysed according to qualitative content analysis. The interviews were transcribed using verbatim as soon as possible after the interview. Then they were read through several times by authors to become familiarised with the material. The working process followed the guidelines for content analysis according to Graneheim and Lundman (2004). The text was analysed

Study	Igelstrom 2012[23]
	in several steps, starting with dividing the text into content areas, and continuing with identifying meaning units that were condensed and labelled with code. All codes in all the interviews were then abstracted into manifest categories and latent themes.
Methods and analysis	data were analysed according to qualitative content analysis
Findings	Theme 1: An incentive strong enough – to have a strong incentive to engage in physical activity was crucial for informants. Consequences of OSA and Obesity. Reasons for devoting oneself to physical activity. Positive outcomes. Side effects. Ambivalence.
	Theme 2: Facilitators of success and challenges to overcome – when the informants were asked to mention what may influence their engagement in physical activity, a wide range of aspects emerged from the data, and these formed three categories: Thoughts and feelings, external circumstances, and disease and physical symptoms.
Limitations and applicability of evidence	No notable limitations

Study	Ingadottir 2006[24]
Aim	To describe patients' and families' experience of long-term home treatment with non-invasive ventilation during sleep with or without additional oxygen therapy.
Population	The person had to have been dependent on technology in the form of non-invasive ventilation with or without long-term oxygen therapy for at least 6 months due to sleep-related breathing disorders, have a spouse or a significant other, demonstrate capability and willingness to verbalize experience, live at home and be between 40 and 70 years of age. Both men and women were to be selected
Setting	Sleep clinic belonging to the lung unit of Landspitali University Hospital in Reykjavik, Iceland,
Study design	Semi structured interviews
Methods and analysis	The interviews were ended when the quality of the information collected was estimated sufficient against the purpose of the study (27), characterized by richness and redundancy (23). The researcher also wrote a diary where she jotted down thoughts related to the context of the interviews and the data analysis, which became a part of the data
Findings	Mixed blessing: life-saving treatment – meaningless exertion - Aspects were split as to the experience of using non-invasive ventilation treatment. It was either seen as a complete life saver or considered meaningless exertion. Sometimes the oxygen treatment was in the role of the life saver and the ventilator treatment was seen as less helpful and vice versa. This depended on the underlying disease and its influence. In cases of hypoventilation and sleep apnoea, using the ventilator was experienced as a major relief and an absolute necessity for survival. Despite these benefits, the patients found it hard to adjust to the treatment in the beginning as it provoked mixed feelings and a struggle. The primary difficulties were to endure the air blowing from the ventilator under heavy

Study	Ingadottir 2006[24]
	pressure and to have to wear a face mask. Participants found it most helpful to force themselves to take an optimistic stance on the treatment, particularly in the beginning, if things did not work properly.
	Compassion and understanding central amid use of complex machines - Closely interwoven into the experience of starting and continuing treatment was the interaction with health professionals. Experiencing compassion and empathy from health professionals was of most importance to them in order to be able to use the machines successfully. The way the treatment was introduced and installed set the stage for what came later. Careful guidance as to how to use the machines, being a part of the decision-making process and being able to access assistance when needed, was valued.
	Listening to the body - Before the patients had started the treatment they had become seriously ill, sometimes repeatedly, without realizing what was going on in their body. They had several symptoms of disturbed breathing during sleep without having a clue of what was happening. The treatment became a turning point in their life and with it their sense of their body changed.
	Wanting to be seen as healthy - Being seen with oxygen tank, ventilation mask or even the notion of somebody knowing that they might be using such things was an issue for the patients.
	Dominance of technological thinking - Despite the fact that the utilization of the machines was not always helpful it did not occur to the participants to stop using them and they tended to focus only on that which was of benefit to them. The treatment was initiated without really exploring the patients' or the families' preferences. Somehow it got started and then one thing followed another.
	Sustained work in maintaining the treatment - The usage of the home ventilator and oxygen not only required constant commitment and time, it also put limitations on several daily life and recreational activities. Capability to travel diminished and some even stopped travelling, which led to isolation. The treatment required attention to the mask, headgear and tubes, which had to be kept clean and the filters changed according to a protocol. The ventilator took up quite some space in the home. Some users of oxygen compressors placed the machine outside their bedroom during night because of the noise it generated.
Limitations and applicability of evidence	No notable limitations

Study	Luyster 2016[32]
Aim	To explore patients' and partners' experiences of CPAP and facilitators and barriers to CPAP use, and elicited suggestions for a first-time CPAP user program.
Population	To participate in the study, patients had to be over 21 years of age and currently treated for OSA with CPAP. Partners had to be over 21 years of age and married to or in a relationship and sharing a residence with the individual currently being treated for OSA with CPAP.
Setting	University of Pittsburgh Medical Centre Sleep Medicine Centre

Study	Luyster 2016[32]
Study design	Eight focus groups were conducted between June 2012 and March 2013 until data saturation was achieved.
Methods and analysis	Inductive content analysis was employed, in order to describe the experiences of OSA and CPAP of patients and partners without imposing preconceived categories but rather allowing categories and names of categories to evolve from the data To derive these categories, each transcript was read entirely for an overall assessment by two experienced coders.
Findings	Knowledge of sleep apnoea - Patients’ descriptions of sleep apnoea were mostly vague and limited to stopping breathing during sleep. Two patients did explain that cessation of breathing at night is due to closing of the airway. Some patients understood that these pauses in breathing disrupt sleep and cause awakenings but that individuals will sometimes not awaken during these episodes
	Effects of sleep apnoea - When asked how sleep apnoea affected their quality of life, patients often talked about the daytime effects of sleep apnoea including decreased energy, napping, daytime sleepiness, irritability, and morning headaches.
	Effects of CPAP - Patients voiced both positive and negative initial experiences with CPAP when first using it in their homes. Many patients talked about problems with the mask and/or pressure at first, but most were able to adjust to wearing CPAP at night.
	Barriers and motivations for CPAP use - Patients and partners described problems with the equipment, interference with sleep and Intimacy, logistical issues, side effects of CPAP, lack of support from healthcare providers, and initial feelings of shame as barriers to CPAP adherence.
	New user support program - Patients and partners suggested format options and important components that would be valuable in developing a program to help first-time CPAP users feel comfortable using CPAP. Small group sessions led by a respiratory therapist and/or a current CPAP user or an online video were identified by patients as optimal formats for providing the program. Having an opportunity to ask questions and having a hands-on demonstration for setting up the machine and becoming familiar with different mask options were emphasized as important components of the program that could help prepare new users.
Limitations and applicability of evidence	No notable limitations

Study	Murphy 2000[33]
Aim	To determine if an instructional videotape was more effective for increasing short-term knowledge about sleep apnoea than a simplified brochure designed at the same literacy level, and elicit qualitative feedback from patients about video and written material to be used for future patient education.
Population	Sleep disorder patients. Of the 192 consecutive sleep disorder patients, 79 (41%)were black, 112 (58%) were white, and 1 (1 %) was of other ethnicity. Subjects ranged from 18 to 72 years (mean, 45 years) 46 % were women, and 54% were men. The most common diagnoses among public and private patients, respectively, were obstructive sleep apnoea (85% and 73%), narcolepsy (6% and 13%),

Study	Murphy 2000[33]
	and other diagnoses (9% and 13%), so that obstructive sleep apnoea totalled 82 %, narcolepsy 10%. The mean reported educational level (last level completed in school) was 12th grade with range from third grade to postgraduate education.
Setting	Louisiana state university health sciences centre sleep clinic, and sleep centre laboratory were asked to participate. The private clinic serves predominantly insured patients.
Study design	Patients watched either an instructional videotape about sleep apnoea or read a newly designed brochure, then responded to a structured questionnaire containing 11 knowledge-based questions and 1 open-ended question (requesting suggestions for improvement of the brochure or videotape).
Methods and analysis	All data were collected and entered into a database using Excel software. Statistical package for Social Sciences software (SPSS) was used to calculate descriptive statistics. Chi-square tests were used to estimate differences between literacy levels and comprehension questions.
Findings	Patients suggested more information on treatment options (they specifically requested better explanation of surgical options) and what preparation they should expect for their polysomnogram. Specific concerns about polysomnogram included the attire for testing and what would happen if they needed to get up during the night.
	Several patients wanted feedback from patients who had the same treatments.
	Patients also stated that they wanted brochures and videotapes using fewer polysyllabic words and more personal communication. Some of the words were too difficult to understand and lacked the positive tone. The complexity of the words removed the emotion needed to deliver a clear message, and patients suggested more personal communication was needed to explain the treatments.
	The suggestion was made to include clear and complete steps of treatments, choosing words that are simple and relative to the patient’s concerns.
	More ethnic representation was requested from number of patients; patients wanted to be able to identify with the patient used as an example.
Limitations and applicability of evidence	Recruitment of larger sample of patients is needed. This study represents one region in the USA and two ethnic groups; thus, representation from various regions is warranted.

Study	Shaw 2012[44]
Aim	To ascertain barriers preventing or delaying OSA evaluation and treatment in black community.
Population	39 black men and women with OSA, aged ≥18 years

Study	Shaw 2012[44]
Setting	Conducted at the State University of New York (SUNY) Downstate Medical Center in Brooklyn to ascertain barriers preventing or delaying OSA evaluation and treatment.
Study design	Five focus groups
Methods and analysis	All focus group discussions were recorded and transcribed verbatim. Field notes were also taken for examination of contextual information and general impressions during the sessions. Initial a priori codes were developed to guide the initial coding phase of the analysis. Emerging themes were identified through the peer review process and led to the development of a coding book. The final phase of the analysis was guided by grounded theory.35 The final data were uploaded into NVivo software (version 8, QSR International, Australia) for coding and qualitative analysis. An example of the analysis process is given in Table 1 and 2, showing a priori and emerging themes with corresponding codes and subcategories. Members of the research team were involved in the coding and analytical phase and contributed to the interpretation of the data based on their differing professional expertise. Peer debriefing sessions were also conducted to minimize bias in the data analysis.
	Perceptions Regarding Definition, Aetiology, and Consequences of Obstructive Sleep Apnoea - Participants' responses about their perceptions of obstructive sleep apnoea fell into 3 categories: a type of insomnia, an age-related phenomenon, and caused by certain bedtime activities (dietary).
	Environmental Barriers to Evaluation for Obstructive Sleep Apnoea - When asked about barriers to having an overnight assessment for sleep apnoea, participants' responses focused on environmental factors such as sleeping in a strange environment, being watched while they sleep, and not having a clear understanding of what the sleep assessment entails.
	Physical and Social Barriers to Treatment Adoption of Continuous Positive Airway Pressure - Across all groups, awareness and knowledge of CPAP treatment were very low, as only one of the study participants had ever come into contact with the device, through a relative.
Limitations and applicability of evidence	One key limitation of the study was related to the convenience sampling method used to recruit the participants. Although this technique has the advantage of being fast and easy to implement, it presents high risks of systematic bias and lack of generalizability of the results. Finally, another limitation of this study related to the lack of representation of other racial and ethnic groups. This limits the ability to explore variations in themes, as they may not be unique to black patients and may reflect larger social or cultural phenomena.

Study	Sporndly-Nees 2014[46]
Aim	The aim of this study was to identify personal conceptions of prerequisites for eating behaviour change.
Population	15 patients with obstructive sleep apnoea syndrome (OSAS; apnoea-hypopnoea index >15) and obesity (Mean body mass index 38.2).

Study	Sporndly-Nees 2014[46]
Setting	Patients were recruited from the sleep laboratory at the department of sleep sciences, respiratory medicine and Allergology, Uppsala University hospital, Sweden.
Study design	Semi-structured interviews were conducted and data were transcribed and analysed using qualitative content analysis was performed on the data according to the structure presented by Grahenheim and Lundman.
Methods and analysis	content analysis was performed on the data according to the structure presented by Grahenheim and Lundman.
Findings	Barriers – Desire and reward, Cravings and emotional control, Low self-confidence, Insufficient support, taxing behaviours, Cost, Perceived helplessness, Low susceptibility
	Facilitators – Positive expectations, Fear of negative consequences, Experience of success, Support and follow up, Accessibility, Applied skills for healthy eating, personal involvement, Challenged self-image
Limitations and applicability of evidence	No notable limitations

Study	Stalkrantz 2012[47]
Aim	The aim of this study was to generate a theoretical model describing concerns for spouses of patients with untreated obstructive sleep apnoea syndrome (OSAS) and how they manage these concerns in their everyday life.
Population	12 spouses of patients with Sleep apnoea
Setting	Not stated
Study design	Interviews
Methods and analysis	The interviews were analysed according to the Grounded Theory method as described by Strauss and Corbin. As described by Strauss and Corbin (26), collection of data and analysis thereof were performed in parallel, where the analysis followed the steps in a hierarchic process. The analysis process started from the first interview, which generated data, ideas and suggestions for theories.
Findings	Social adjustment - Social Adjustment' includes two categories that reveal different reactions to adjustments required by their partners' symptoms. The first category 'Limited circumstances' describes a feeling of lack of control, i.e. social adjustments. This could mean that they experienced limited time for their daily activities, e.g. on those days that their partner was tired, they received less help at home. The spouses also felt that the time for their own activities was decreased. The second category, 'Same circumstances',

Study	Stalkrantz 2012[47]
	Conversely describes how the spouses were able to see the social adjustments as less of an issue of lack of control and more as a challenging circumstance requiring compromise.
	New feelings - The second main category in the model, 'New feelings', reveals the emotional reactions that had changed during the years of the spouses living with an ill partner. These emotional reactions were related to the effects of their partner's OSAS and the impact it had on the spouse's everyday life.
	Sacrificing - Sacrificing was one way of managing everyday life for the spouses family and missed the support from their partners in getting help with everyday chores. The sacrifices the spouses did were connected with their partner's tiredness and its consequences, but even their own tiredness led to their not having as much energy as earlier.
	Controlling - Controlling was another way of managing the life situation. The spouses felt they needed to have control, in everyday life, as well as during the night, in relation to their partner's OSAS. Control was their own choice, but was perceived as a necessity in relation to the worry and anxiety they felt about their partner's OSAS symptoms
	Changing - Changing was also a way of managing the everyday life. To make do different types of changes could help both the spouses, as well as their partners. The spouses expressed both fear and anxiety about the future, both concerning their own and their partner's health.
	Understanding - Understanding meant that even how hard it was for the spouses in their everyday life, it was important to have an Understanding for their partners OSAS, as a way of managing the situation. Despite the anger over not being able to sleep properly and tiredness during the day, the spouses still described feelings of empathy as they felt sorry for their partner, because it was not his/her fault to suffer from OSAS. 'It must be dead tough.
Limitations and applicability of evidence	No notable limitations

Study	Tyrrell 2006[48]
Aim	Study explored patients understanding and experiences of their OSA and of the CPAP therapy and their reasons for stopping treatment.
Population	Nine patients were interviewed (age 32-70 years; 8 males).
Setting	Homecare agency (AGIradom) that is part of the French Respiratory Homecare Network.
Study design	Semi-structured interviews, constructed from the Health Belief Model (HBM), Each interview was recorded for re-transcription and lasted about 1 hour. The patient responses were subsequently classified according to the HBM grill.

Study	Tyrrell 2006[48]
Methods and analysis	Health belief model.
Findings	Understanding and impact of OSAHS – four of the nine patients were not clear about the nature or mechanisms of their sleep disorder and could only vague explanations.
	Understanding and experience of CPAP – Patients’ levels of understanding were highly variable, despite the fact that all patients had received basic education about the treatment before embarking on CPAP therapy
	Decision to abandon CPAP therapy – when questioned about stopping CPAP treatment; seven specified that they did not because of their negative experiences, despite family encouragement to continue therapy in four of these cases.
	Mental health questionnaire – three patients scored over threshold score for anxiety, and one patient scored as depressed on HAD questionnaire. Content of the interviews shoved that at least three patients were suffering from some degree of depressive symptomatology, as they made frequent references throughout the interview to poor morale and negative mood states.
Limitations and applicability of evidence	No notable limitations

Study	Veale 2002[49]
Aim	To seek an in-depth analysis of how patients live with sleep apnoea by allowing them an open discourse and analysing the text of their statements.
Population	Thirty patients entering a pulmonary rehabilitation and convalescent centre for consideration for treatment of sleep apnoea were interviewed. The subjects (20 male:10 female) were aged 39 to 74 (median 55 yrs). Seven were widowed and these were predominantly women. Many of the patients were retired but eight of the patients under the age of 60 were registered as incapacitated. The patients weighed between 53 and 167 kg (median 100 kg). The OSAS was severe in many cases with the apnoea plus hypopnoea index between 11 and 169 per hour of sleep (median 80 hr)1) measured by full polysomnography. Eight of the patients also had chronic obstructive airways disease and five had diabetes. As the patients were interviewed in a rehabilitation unit, 15 were in the initial stages of CPAP treatment.
Setting	Pulmonary rehabilitation and convalescent centre

Study	Veale 2002[49]
Study design	A trained psychologist conducted semi-directive interviews with patients attending a pulmonary rehabilitation and convalescent unit around themes of sleep, health and treatment. An analysis of content and of discourse was carried out by textual analysis and by propositional analysis of discourse (PAD) with the aid of dedicated computer programs (Tropes, Sphinx Lexica)
Methods and analysis	Three types of analysis were performed on the text: (1) A semi-automatic analysis of the text by a computer program called Tropes (Tropes version2.0) (ACETIC, Paris, 1997). This was a form of semantic analysis called propositional analysis of discourse (PAD). It consists of an analysis of clauses in a text. (2) A manual analysis by a psychologist trained in the techniques of content analysis. (3) A lexical analysis by a computer programme called Sphinx Lexica (version 2Le Sphinx development, Seynod 74600 France).
	Tropes analysis - All the discourse of the 30 patients was cut into 3488 clauses. The subjects used predominantly verbs of action ('I do') (45%), rather than verbs of being ('I am') (38%) or verbs of self-affirmation (17%). There were no verbs expressing a wish to influence the listener since her role was neutral. Qualifications were mostly those of intensity (45%) but there were many negative (20%) and opposing conjunctions (26.5%). It should be noted that in the analysis of the FN negative qualifications were not treated apart. Temporal clauses were also numerous (17%) as well as temporal conjunctions (17%). The personal pronoun 'I' was the subject of the discourse in 60% of clauses.
	Manual analysis - A psychologist trained in discourse analysis (GP) performed an initial subjective examination of the text for clauses referring to particular contexts [14]. Each clause was attributed one or several codes depending on its content. The results of the Tropes analysis were used as pointers for the classification of the clauses. All themes in the discourse of each individual were classified and tabulated until every theme raised had been defined. This was a subjective categorisation by the researcher creating the codes. The style of speaking was classified into positive or negative categories. Some themes could be regrouped but there were more themes than patients since each individual cited a number of themes in response to a prompt by the interviewer. For instance when asked to discuss their illness some discussed their snoring, their fatigue and their weight problems.
	Shinx Lexica analysis - Twelve open questions yielded 45 different themes, including anxiety in 22 cases. Only six patients did not have some element of current or previous depression. All subjects had co-morbidity with sleep apnoea, for example obesity in 83% of cases. The possibility of sleep apnoea was often raised indirectly when the patient was seen for some other health problem. Those who reported fatigue and sleepiness often used the term exhausted or beat to signify the sudden desire to sleep. An additional worry evoked in these themes was the occurrence of near accidents in relation to episodes of sleepiness (40%). There were also episodes of breathlessness (23.3%) and episodes of irritability due to fatigue (13.3%). Many patients found this very disturbing as it created the greatest difficulties in daily life. One third of subjects referred to loss of memory in association with OSAS but no specific vocabulary was used. Sixty percent of subjects felt that they could die from an apnoea and 20% were preoccupied by this idea while others felt fatalistic. Sixty seven percent of subjects felt an anxiety that was usually mild or recently improved. A number of subjects were anxious about the prospect of CPAP (26.7%), but generally resigned to its use (43.3%).

Study	Veale 2002[49]
Limitations and applicability of evidence	Since the analysis by Tropes was completely automatic, there was no subjective bias which could be a problem in manual types of content analysis. However, there persists an element of subjectivity in our study since we combined different types of analysis. This is essential in order not to lose all the elements that were of interest for the patient.

Study	Vlachantoni 2015[51]
Aim	To evaluate the prevalence of morning and day sleepiness and obstructive sleep apnoea syndrome (OSAHS) among taxi drivers of the Athens airport and to examine the factors that may influence a taxi driver's decision to participate in screening.
Population	The sample consisted of 840 professional taxi drivers - only 10 patients participated in the qualitative assessment. Ninety-seven percent of the drivers were male, mostly overweight (mean BMI 29.1kg/m^2), middle-aged (mean age 44.5 yrs) and active smokers (68.1%). They worked an average of 11.6 hours per day and most (57.2%) worked 7 days per week, with the most frequent working shift being the day shift -from 05.00 to 17.00- (54.3%), followed by the night shift and alternate shift -one week of day shifts followed by a week of night shifts working from 17.00 to 05.00.
Setting	Athens International Airporttaxi waiting area.
Study design	Self-administered questionnaire A qualitative study was conducted to determine the reasons why, 75% of the taxi drivers considered high-risk for sleep apnoea and offered a cost-free examination at the Sleep Clinic, opted to decline. Drivers were recruited randomly from the above mentioned group and one-to-one semi-structured interviews were conducted. Seven drivers declined to participate and recruitment continued a data saturation point was reached.
Methods and analysis	All interviews were audio-taped, transcribed verbatim and checked for accuracy. Transcribed one-to-one interviews were formally analysed using Thematic Analysis13, a qualitative analytic study that involves the exploration of the participant's personal experience and perception of a certain subject and is concerned in interpreting this perception through the researcher's lenses. Line-by-line analyses were used to generate common themes and patterns addressing the research question and theoretical connections between them.
Findings	Attitudes towards their personal health - Drivers were found not to consider personal health a priority and, as a consequence to dedicate little or no time on maintaining it. Drivers described taxi-driving job in general as a profession that leaves little or no time for extra-curricular activities. Work is generally prioritized over family time
	Taxi drivers' standing on prevention - Overall, although drivers viewed prevention positively, they valued the practical implementation of preventive health care as difficult. The lack of feasibility regarding implementing preventive measures was attributed to the health system organization, their own lack of motivation but also to the fear of what they might discover when undertaking medical exams.
	Health issues prioritization – taxi drivers stated that they have other priorities or even have no choice but to deny themselves any action that may improve their health status.
	Drivers suggestions for effective participation in research projects - Taxi drivers' suggestions on ways to approach their professional group more effectively and yield better participation in future screening programs revealed an effort

Study	Vlachantoni 2015[51]
	to by-pass directly or indirectly their most common and shared problem which was not making enough money on a daily basis to cover their needs. Drivers suggested the possibility of arranging for medical exams or doctor's visit at a site close to their work environment and more specifically near their waiting or parking area. Participants cited also the possibility of offering monetary incentives as well as no waiting time for the test to drivers who complete the screening process.
Limitations and applicability of evidence	No notable limitations

Study	Waldman 2020[52]
Aim	To explore the experiences of adherence to CPAP treatment in patients with OSAHS.
Population	42 participants currently experiencing EDS with OSA, thirty participants (71%) discussed their reasons for ultimately seeking medical attention for their OSA symptoms.
Setting	3 US cities: New York City, Dallas, and Los Angeles. Recruitment was conducted via a professional market research organization, utilizing their proprietary databases of potential study participants consisting of people with a range of health conditions who had previously indicated an interest in participating in a research study after having been identified through multiple recruitment strategies, including advocacy organizations, patient support groups, online marketing, live events and community activity. All focus groups were conducted in person at focus group facilities and moderated in English by professionals experienced in focus group leadership (co-authors L Waldman and M Brod).
Study design	Semi-structured focus groups
Methods and analysis	Data were qualitatively analyzed through an adapted grounded theory approach, entailing developing and refining a theory based on concepts derived during the research process [44]. Transcripts were analyzed for content using Dedoose (www.dedoose.com), a qualitative analysis software program. A preliminary code list was created based on the discussion guide's sensitizing (initial, general) concepts [45] and subsequently revised based on concepts derived from the focus groups during the coding process.
Findings	Reasons for seeking medical care - the primary reasons were due to input from spouse/partner, another family member, or friend (n = 20, 67%), the participant's own concern about particular symptoms (n = 7, 23%), and/or falling asleep while driving (n = 5, 17%). Small numbers also reported seeking medical attention due to having a comorbidity (n = 2, 7%), falling asleep at work (n = 2, 7%), having a car accident due to EDS (n = 1, 3%), being required by an employer (n = 1, 3%), and seeing a sleep study advertisement (n = 1, 3%).
Limitations and applicability of evidence	No notable limitations

Study	Ward 2017[54]
Aim	To explore experiences of living with this therapy from participants' perspectives using constructionist grounded theory.
Population	Adult participants (n = 16) were recruited through a main-centre respiratory service in New Zealand
Setting	Respiratory clinic in the main city of New Zealand.
Study design	Semi-structured interviews and data were analysed until theoretical saturation was reached. Constructionist grounded theory study.
Methods and analysis	This paper uses consolidated criteria for reporting qualitative studies (COREQ) checklist.
Findings	Becoming good sleep team – Began with partners and occasionally family or friends, bearing witness to the symptoms of OSA, leading to poor sleep for both witnesses and snorers. By bargaining and sharing their experiences, witnesses enabled snorers to start becoming aware of OSA symptoms, such as constant daytime fatigue. Through negotiating and joint decision making snorer and partner became a team who shared a goal of good sleep, illustrating the third subcategory of becoming a team. By being a team and becoming aware, snorers reached a limit signified by the choice to act, and improve sleep by seeking medical help.
	Making choices about CPAP – on receiving a CPAP device, participants began making choices about CPAP, the second category reported in this paper and comprising the subcategories reacting to CPAP, become motivated, and acting by overcoming barriers or by yielding to barriers. Through bargaining and balancing, personally and with their partner, participants processed reactions to needing CPAP and developed motivations regarding CPAP use.
	Becoming used to CPAP – Patients who remained motivated and persevered with the choice to use CPAP started becoming used to CPAP, the final category. Participants made adaptations to integrate CPAP into daily life choosing new routines. Once the challenges of using CPAP had receded, getting used to CPAP became relatively straightforward. In the presence of time and perseverance, mastering CPAP became possible. CPAP became normal and routine part of life that no longer required conscious effort but retained importance in maintaining good sleep for users and partners.
Limitations and applicability of evidence	No notable limitations

Study	Ward 2018[53]
Aim	To explore experiences of living with CPAP therapy from participants' perspective using constructionist grounded theory.
Population	Adult patients with sleep apnoea, Age: (25-35) – 2 participants; (36 – 45)- 4 participants; (46 – 55) – 2 participants; (56 – 65) - 6 participants; (65+) 2 participants. Ethnicity: New Zealand European -9; Maori -1; Samoan – 1; Indian – 3; NZ European plus other – 2;
Setting	Main-centre respiratory service in New Zealand

Study	Ward 2018[53]
Study design	Semi-structured interviews
Methods and analysis	Constructionist grounded theory – Interviews began with open ended questions, or prompts to elicit information relevant to the participant regarding CPAP. Data collection and analysis occur concurrently in GT. Therefore, analysis commenced with line by line coding of the first transcript to identify initial constructs. Further coding using gerunds to identify action enabled clustering of data into categories.
Findings	Becoming a team for good sleep – through becoming aware and being a team, snorers reached a limit signified, by the point at which they reached a limit signified by the point at which they chose to act in favour of improving sleep by seeking medical help. This process begins with those close to the snorer bearing witness.
	Bearing witness – without testimony of loved ones, most CPAP-user participants claimed they would have remained ignorant of sleep apnoea symptoms.
	Becoming aware – If it were not for their witnesses, most CPAP users confessed to remaining ignorant of their sleep apnoea.
	Being a team – CPAP-users attributed their success using CPAP to collaborative nature of close relationships.
Limitations and applicability of evidence	This small study was conducted in only one region of New Zealand and represents the start of change to treatment implementation, and warrants further research about factors necessary for success with CPAP identified in this study.

Study	Willman 2012[55]
Aim	The purpose of this study was to describe patients' experiences of CPAP treatment in obese individuals with moderate to severe OSAS.
Population	Men and women, moderate or severe obstructive sleep apnoea(AHI>15), obesity (BMI over 30 kg/m^2)
Setting	Laboratory at the department of lung medicine, Uppsala University Hospital, Sweden.
Study design	Semi-structured interviews.
Methods and analysis	A qualitative content analysis was employed. Fifteen participants were consecutively selected. Data were collected by semi-structured interviews.
Findings	Coming to terms with wearing CPAP - most of the people experienced difficulty with CPAP machine. It was hard getting used to the machine and the physical discomfort, as well as handling the device, caused a lot of irritation. Even so, there was satisfaction enough to use the CPAP close to every night and some accepted it from the onset.
	Getting a new life – All of the patients experienced a positive difference with CPAP and life improved in a lot of different ways – they slept better, were more alert and had more energy to do more things than before.

Study	Willman 2012[55]
	Being restricted in everyday life – the use of CPAP brought with it drawbacks that affected life. Consequences on social life. Return of symptoms. Consequences in bed
Limitations and applicability of evidence	No notable limitations

Study	Ye 2017[56]
Aim	To identify facilitators and barriers to successful treatment of one of the most common sleep disorders, obstructive sleep apnoea, with continuous positive airway pressure (CPAP).
Population	20 patients with obstructive sleep apnoea
Setting	Patients were recruited from the patient population seeking medical attention for OSA at 2 large participating urban hospitals in the north eastern region of the United States.
Study design	20 joint qualitative Semi-structured interviews
Methods and analysis	This qualitative analysis used a dyadic approach to identify facilitators and barriers to successful treatment of one of the most common sleep disorders, obstructive sleep apnoea, with continuous positive airway pressure (CPAP).
Findings	Facilitators of CPAP use - The CPAP patient's partner aiding diagnosis and treatment; Couples working together using CPAP: joint coping; Perceived benefits of CPAP for both partners; The patient being motivated to use CPAP for the partner; Support provided by the partner for CPAP use
	Barriers of CPAP use - Anxiety related to CPAP treatment particularly in the beginning of therapy; Bothersome equipment causing disruptions in sleep and bedtime routine; Interruptions to intimacy; Concern about image change while wearing CPAP;
	What we wish we would have known: The wish to start CPAP treatment sooner; The need for reciprocity toward each other; Having patience with each other”
Limitations and applicability of evidence	No notable limitations

Study	Zarhin 2015[57]
Aim	To examine whether and how the ways in which OSA emerged affect patients.

Study	Zarhin 2015[57]
Population	65 Israelis who received a laboratory diagnosis of OSA sometime in 18 months prior to the interview.
Setting	Big hospital based sleep centre, which is located in the Tel-Aviv metropolitan area and functions as both a laboratory and clinic.
Study design	In depth interviews
Methods and analysis	The interviews were transcribed verbatim and uploaded onto ATLAS.ti. (ATLAS.ti Scientific Software Development, Berlin), a software for qualitative data analysis, where the interviews were coded thematically and analysed based on constructivist grounded theory principles, including systematic conceptualisation, constant comparisons, coding, and memo writing (Charmaz 2006). Most of the comparison process was done through an elaborate and careful process of coding and grouping the codes into concepts in a hierarchical manner in an attempt to construct a theory 'from the ground up' (Wasserman et al. 2009).
Findings	Patients reception of OSA diagnosis - While most of the participants in this study did not reject their diagnoses completely, about a third expressed doubts and scepticism towards it. Some 'doubters' tended to prioritise symptoms (especially daytime sleepiness), and clinical signs (particularly obesity), implicitly or explicitly criticising the exclusion of these factors from the definition of OSA while relying on a specific image of the OSA patient as sleepy and obese. Other patients also disapproved of the diagnostic procedures and technology by suggesting that 'laboratory sleep' is not an accurate indicator of their quality of sleep at home.
	Prioritising symptoms and clinical signs - Whereas the current biomedical model prioritises laboratory measurements over clinical signs and symptoms, some respondents prioritised the latter. As clinical guidelines instruct, at this setting, the AHI was the primary determinant of the existence and severity of OSA. The existence of clinical signs and symptoms often affect patients' decisions to consult a Primary Care Physician (PCP), an Ear, Nose, and Throat (ENT) specialist, or a neurologist who then might suspect OSA and provide a referral to see a sleep specialist. Once the patient reaches the sleep centre, however, laboratory measurements take precedence over the presence of symptoms. In this study, most of the respondents sought medical care because they suffered from one or more symptoms, such as fatigue, disturbed sleep, or habitual snoring. Nevertheless, after receiving an OSA diagnosis, many respondents criticised its medical model, refusing to believe that they could be suffering from this sleep disorder while lacking the specific symptoms and signs they associated with it, including excessive daytime sleepiness, obesity, and very loud snoring.
	Criticising 'laboratory sleep' - A number of respondents were unconvinced that 'laboratory sleep' could reflect their quality of sleep at home. During sleep studies, technicians place sensors on multiple parts of the body, to measure the patient's breathing, heart rhythm, movement, and stages of sleep. According to some patients, these conditions tampered with their quality of sleep, such that it was dissimilar to their 'average' sleep. Several respondents also asserted that the tension they felt prior to and during the sleep study affected their sleep, thus expressing a view of sleep processes as influenced not only by physiological factors, but also mental ones.
Limitations and applicability of evidence	No notable limitations

Study	Zarhin 2017[58]
Aim	To understand patients experiences of CPAP use vs non use
Population	This study draws on in-depth interviews with 61 Jewish-Israeli patients with OSA who received a recommendation to use a CPAP device. The sample includes both patients who started using CPAP devices as well as patients who rejected this course of treatment. The sample comprises 61 Jewish-Israeli patients (28 women and 33 men) who received an OSA diagnosis sometime in the 18 months prior to the interview (see endnote B). This period of time is close enough to diagnosis to allow for good recollection of what happened since then and far enough to examine what happens to adherence. Apnoea-hypopnea index (AHI) was available for 60 respondents. AHI average was 48.6 ± 28 (range 13–129.4). Scores of Epworth Sleepiness Scale were available for only 48 of the respondents, with an average of 9.6 ± 5.3 (range 0–23). Most of the participants (n = 51) were married at the time of the interview and 1 respondent was living with a partner. The rest were either divorced (n = 6), separated (n = 1), or widowers (n = 2). Except for 2 men, all respondents had children. Although most participants were employed (n = 42), approximately one-third were either unemployed (n = 7) or retired (n = 12). The majority of respondents reported that they belong to the middle class (n = 44), but a few (n = 12) said they belong to the working class.
Setting	Sleep centre located in the Tel-Aviv metropolitan area, Israel
Study design	In-depth interviews
Methods and analysis	The interviews were transcribed verbatim and uploaded onto ATLAS.ti. (Scientific Software Development GmbH, Berlin, Germany), a program for qualitative data analysis, where the interviews were coded and analysed based on constructivist grounded theory principles, including systematic conceptualization, constant comparisons, coding, and memo-writing. The first author conducted the comparison process through an elaborate and careful process of coding and grouping the codes into concepts in a hierarchical manner. Specifically, coding comprised 3 stages. During the initial coding stage, the first author used open coding, giving temporary labels to phrases and incidents in the interviews to capture their meanings and content, and exploring all the theoretical possibilities in the data. The second stage of coding included focused coding in which the first author used codes that were more frequent and significant. Codes that endured this process were densified into categories, moving from a descriptive level to a more abstract theoretical level. In the third stage, the author moved on to theoretical coding in which she specified how the substantive codes related to one another, and then arranged the concepts that emerged into theoretical propositions.
Findings	USERS' experiences - Feeling uncertain about the role of CPAP in improving symptoms and quality of life - The 11 adherent CPAP users were generally pleased with the device's effects on their daytime and night-time symptoms. They felt more rested and energetic during the day and experienced fewer awakenings at night. Respondents addressed the improvement in symptoms and quality of life as one of the major benefits of the device. However, they did not credit the improvement in their condition solely to the device. Rather, they kept pondering whether other factors, such as reduced stress due to retirement or reduction in workload, as well as weight loss and exercise, contributed to their recuperation. In other words, in spite of the benefits they obtained, they were ambivalent about the exact role of CPAP in what they called their "recovery" or "improvement."

Study	Zarhin 2017[58]
	USERS’ experiences - Experiencing difficulties with CPAP use, expecting a cure - With one exception, all of the patients who used CPAP on a regular basis also expressed substantial reservations and resentment toward this device. They criticized medicine for not improving PAP therapy, arguing that developers should attempt to make the device “more elegant” and “user friendly.”
	USERS’ experiences - Comparing home to hospital – In the home setting, they began experiencing problems and challenges they had not necessarily encountered at the centre. At home, respondents do not necessarily assume the patient role. Instead, social expectations demand that they return to their regular role obligations as caregivers, workers, etc. However, as respondents attested, wearing “an external,” “ugly” and uncomfortable device is commensurate with people’s expectations for being at a hospital, a setting that requires people to relinquish some control over their bodies and subject themselves to inspection and bodily manipulation. In their own homes, however, people expect to maintain bodily control. Even respondents who felt very refreshed after their trial night with CPAP said this experience did not recur at home. Their nights at home were not as “peaceful” and “restful” compared to their trial night. Rather, it was filled with additional struggles and difficulties due to the CPAP. Thus, although users expressed gratitude for the “healing prospects” of the CPAP, they resented how it made them feel physically and emotionally.
	USERS’ experiences – Reducing adherence - Four respondents stopped using the device (non-adherent users) and 4 more started using it only occasionally (partially adherent users). The partially adherent users insinuated they might stop using the device altogether. Two of these respondents grappled with the question of adherence every evening, wondering whether they should use the CPAP or not, whereas the other 2 respondents reached an agreement with their spouses that they use it only on specific nights.
	NONUSERS’ experiences - Experiencing worsened symptoms, reconsidering potential benefits from CPAP use - Of the 42 nonusers, 35 had scruples or second thoughts about not using the CPAP. Those who had not tried CPAP therapy said they often wondered whether they should try the device, whereas those who tried it mulled over whether they should make greater efforts to adjust to it, expressing ambivalence toward their decision.
	NONUSERS’ experiences - Meeting adherent CPAP users - The data indicate that people who know CPAP users that are pleased with the device and use it regularly are more likely to try the device whereas people who only know nonusers are less likely to try it. Still, as the previous section described, although knowing adherent CPAP users may influence people’s willingness to try PAP therapy, it does not ensure long-term Adherence.
	NONUSERS’ experiences - Finding other treatment options to be unsatisfactory - Although 8 respondents found some relief by using these alternative options, the rest said that at the time of the interview, they did not yet find an effective treatment. These respondents stated that “the next step” would be to try (or retry) the CPAP.
Limitations and applicability of evidence	No notable limitations

Appendix E: Forest plots

Not applicable.

Appendix F: Excluded studies

F.1 Excluded clinical studies

Table 11: Studies excluded from the clinical review

Reference	Reason for exclusion
Alebraheem 2018[3]	Incorrect population adolescents
Aalaei 2020[1]	Study done in Iran - non OECD country
Al-Khafaji 2020[2]	Inappropriate study design - not a qualitative study, patients completed self administered questionnaire
Almeida 2013[4]	Incorrect population adolescents
Anni 2020[5]	Inappropriate population - nine family physicians in Ontario who use long-term opioid therapy to treat patients with chronic pain
Boss 2017[6]	Incorrect population SBD of children
Davies 2019[9]	Incorrect populationSBD of infants
Everitt 2014[14]	Incorrect population - patients with insomnia
Flynn 2013[16]	Incorrect population children with tracheostomy
Gentina 2019[18]	Inappropriate study design -patients reported their subjective views regarding their partner's engagement in their CPAP treatment and the quality of their marital relationship using the Quality of Marriage Index.
Goyal 2017[19]	Study done in India- non OECD country
Howard 2019[21]	Inappropriate population - not OSA, patients with sickle cell disease, 90% of adults and 82% of children had RDI <5
Hu 2014[22]	Incorrect population - Taiwan non oecd country
Ioja 2017[25]	Incorrect intervention - structured questionnaire
Jokubauskas 2019[26]	Incorrect intervention - structured survey
Landry 2019[27]	Inappropriate study design - consensus opinion amongst stakeholders,the panel identified key areas that were then formatted into statements that would allow panellists to respond with a level of agreement to each statement
Lavi 2020[28]	Inappropriatestudy design - not a qualitative study, parents completed Parental concern scale questionnaire
Leece 2020[29]	Inappropriate study design: study investigated opioid guideline adherence . wrong population - nine family physicians in Ontario who use long-term opioid therapy to treat patients with chronic pain.
Links 2017[30]	Incorrect population SDB children

Reference	Reason for exclusion
Liu 2020[31]	Inappropriate study design - not a qualitative study, patients completed self administered questionnaire
Olsen 2012[36]	Incorrect intervention motivational interviewing vs no motivational interviewing. structured questionnaires looking at adherence outcomes
Penn 2013[37]	Incorrect population patients with type 2 diabetes
Prashad 2013[38]	Incorrect population adolescents
Reuveni 2004[40]	Incorrect study design
Roberson 2016[41]	Incorrect population - patients undergoing bariatric surgery
Sachs 2017[42]	Incorrect population - patients with diabetes
Shahrabani 2014[43]	Inappropriate intervention Structured questionnaires were used
Soni-Jaiswal 2016[45]	Incorrect population - parents of children with mucopolysaccharosis.
Veer 2020[50]	Inappropriate population- study assessed difficulties that junior doctors faced with interpretation of drug induced sleep endoscopy.