



**Experiences of Using Positive Airway Pressure for Treatment of Obstructive Sleep Apnoea: A
Systematic Review and Thematic Synthesis**

Dr Amy Brown – Lancaster University

Dr Steven Jones – Lancaster University

Dr Guillermo Perez-Algorta – Lancaster University

Corresponding author: Dr Amy Brown, Doctorate in Clinical Psychology, Division of Health and Research,
Faculty of Health and Medicine, Lancaster University; amy.brown@addenbrookes.nhs.uk

Acknowledgements

Thank you to Tanya Williamson, Faculty Librarian, for their expert input around systematic literature searching.

Disclosure Statement

Financial Disclosure: none

Non-financial Disclosure: none

Data Availability Statement

No new data were generated or analysed in support of this research.

Abstract

Study objectives

Sub-optimal use of positive airway pressure (PAP) to treat obstructive sleep apnoea (OSA) continues to be a major challenge to effective treatment. Meanwhile, the individual and societal impacts of untreated OSA make effective treatment a priority. Although extensive research has been conducted into factors that impact PAP use, it is estimated that at least half of users do not use it as prescribed. However, the voice of users is notably minimal in the literature. A systematic review and qualitative metasynthesis of PAP user experience was conducted to contribute to understandings of how PAP is experienced and to inform how usage could be improved.

Methods

PsycINFO, MEDLINE, CINAHL and EMBASE databases were systematically searched. Primary research findings of adult experiences using PAP that had been inductively analysed were included. Papers were critically appraised using the CASP qualitative checklist to generate a “hierarchy of evidence”. Thematic synthesis was then conducted to generate analytical themes. Results were presented in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA).

Results

25 papers reporting on over 398 people’s experiences were analysed to generate 4 themes: Journey to PAP, Discomfort from and around PAP, Adapting to and using PAP, and Benefits from PAP. Author reflexivity and vulnerability to bias is acknowledged.

Conclusions

This metasynthesis gave voice to user experiences of PAP, revealing barriers to PAP use at a healthcare service level across the world. The findings highlight ways in which services may be able to address these barriers to enhance PAP use.

Keywords: Obstructive sleep apnoea (OSA); positive airway pressure; experience; metasynthesis

PROSPERO registration number: CRD42020157767

Statement of Significance

This literature review provides a unique and comprehensive synthesis of the voices of people who use positive airway pressure (PAP) to treat obstructive sleep apnoea. The findings suggest that services can improve the, currently poor, use of PAP through:

- implementing a biopsychosocial approach
- improving awareness of obstructive sleep apnoea in primary care services
- investing in more positive experiences of obstructive sleep apnoea assessment and diagnosis
- providing trials of different PAP equipment
- reducing the cost of PAP to the individual
- providing sufficient information alongside ongoing, coordinated, person-centred support and review
- involving the person and significant others in decisions and goals around PAP
- introducing new PAP users to existing users

The synthesis also highlights avenues that warrant future research.

Experiences of Using Positive Airway Pressure for Treatment of Obstructive Sleep Apnoea: A Systematic Review and Thematic Synthesis

Obstructive sleep apnoea (OSA), the most common sleep-related breathing disorder, involves the upper airway repeatedly obstructing airflow during sleep. Estimated prevalence ranges from 1-19% for females, 2-33% for males¹⁻⁴, and up to 49% for people of advanced age⁴. OSA is linked to serious physical, mental, cognitive and social difficulties⁵⁻¹¹ and reduced sleep and quality of life for bed partners¹². Many cases are believed to go unrecognised^{1,13}, and prevalence is increasing as obesity is a significant risk factor^{4,14}. It is considered that untreated OSA doubles healthcare expenses, largely due to increased cardiovascular risk¹⁵. Effective treatment is crucial to reducing the individual and societal impacts¹⁶. However, evidence suggests that substantial barriers to effective treatment exist which psychological understandings may help address.

Positive airway pressure (PAP or CPAP for continuous) is the first-line treatment for OSA¹⁷⁻²⁰. Recent developments include bilevel (BiPAP), auto-adjusting and flexible PAP²¹. All involve connection to an air supply, covering at least the nostrils and sometimes mouth, to keep the airway inflated overnight. PAP can significantly reduce symptoms and improve health outcomes for people with OSA²²⁻²⁴. However, whilst prescribed usage is at least 4 hours every night, it is estimated that 46-83% of users do not achieve this²⁵, referred to as a lack of “adherence” and/or “compliance”. These usage rates haven’t changed since the introduction of PAP in 1981²⁶, presenting a significant challenge to effective OSA treatment.

Many variables have been identified as operative in PAP adherence. Much research focuses on biomedical factors and has linked usage with body mass index, OSA severity, age and blood oxygen levels^{27,28}. Meanwhile, some research has established links with psychological factors such as health value and beliefs, self-efficacy, coping strategies, low mood and perceived partner support²⁹⁻³⁴. Further research has also found lower PAP use to be associated with ethnic minority status, less education, lower socioeconomic status, living alone, and employment³⁵⁻⁴⁰. PAP side effects, such as mask leakage, nasal stuffiness and

feeling claustrophobic, also affect use⁴¹⁻⁴³. The breadth of variables found to account for the variance in PAP use^{29,44,45} exemplifies the need for a biopsychosocial understanding⁴⁶.

Previous reviews have proposed a biopsychosocial approach, advocating holistic assessment and a person-centred approach to identifying and addressing risks for sub-optimum use^{44,47}. There has been a more recent focus on person-centred care⁴⁸⁻⁵¹ and the development of educational and supportive interventions to improve PAP use⁵²⁻⁵⁵. Despite the suggested efficacy of these interventions, few have progressed beyond research trials, likely due to feasibility and cost^{52,56}. Thus, further understandings of the user experience of PAP may facilitate establishing feasible and cost-effective interventions. A review⁵⁷ concluded that user perspectives within the literature are minimised by medical research paradigms of “compliance” as the ultimate outcome measure, placing users in a non-expert position and silencing their experiences. This review reflected the dominance of quantitative methodology around experiences in the PAP literature and recommended further exploration of qualitative user experiences to determine how PAP use can be improved.

Therefore, a systematic review and metasynthesis of qualitative research detailing first-person experiences was conducted to explore what people’s reported experiences are of using PAP. To the authors’ knowledge, this is the first metasynthesis of its kind. Synthesis of qualitative experiences make important contributions to healthcare innovation and policy⁵⁸. This review aimed to increase awareness of PAP users’ experiences to help understandings of how to support PAP use.

Method

This review followed The Preferred Reporting Items for Systematic Reviews and Meta-Analyses⁵⁹ and Enhancing Transparency in Reporting the Synthesis of Qualitative Research⁶⁰ guidelines. The protocol was pre-registered on PROSPERO (CRD42020157767).

Metasynthesis

A metasynthesis involves collating and further interpreting qualitative findings on a topic from multiple sources⁶¹. Thematic synthesis⁶² is a method of metasynthesis which utilises the principles of

thematic analysis to achieve these ends. This metasynthesis was informed by pragmatism where the contribution of research to improving healthcare and people's lives is prioritised over other considerations⁶³. Thematic synthesis was developed to answer healthcare questions and can be used to synthesise qualitative findings generated from different methodologies and epistemologies⁶². This inclusive methodology was befitting to the review's multidisciplinary scope.

Search

The first author independently searched PsycINFO, MEDLINE, CINAHL and EMBASE databases from inception on January 16th 2020. The Population, Exposure, Outcomes framework (a tool for generating systematic search terms)⁶⁴, papers found through a scoping search, and relevant previous systematic search terms⁵⁷ informed pre-planned free-text search terms. Free-text terms and any relevant thesaurus terms for each PEO framework category were combined with Boolean operator "OR" and these groups were combined with "AND". Table 1 depicts the full search used in MEDLINE alongside differing database-specific thesaurus terms and limits. Due to being the first review of its kind, no date limits were applied. The search strategy was developed in consultation with a subject-specific librarian.

Insert Table 1 here

Eligibility

Primary research papers reporting first-person qualitative experiences of adults (aged 18 or older) using PAP to treat OSA were included. As the first review of its kind, experiences were limited to adult users and accounts from adolescents, caregivers and partners were not included⁶⁵⁻⁶⁷. Included papers must have used an inductive analytic method as thematic synthesis involves further inductive analysis, meaning prior assumptions, theories or hypotheses from deductive methodology could bias the results^{62,68}. Papers also had to be in English and published in a peer-reviewed journal. Papers were excluded if (i) other participants (e.g. partners) contributed data and these findings were not separable; (ii) participants had additional health concerns/needs that are not typical of people with OSA and (iii) discourse analysis was used such that the results focussed on the language used rather than the experiences. Any ambiguities that arose during the application of these criteria were discussed between the authors to agree a decision in

keeping with the aim of the review: to be as comprehensive as pragmatically possible, given that it is the first review of its kind.

Appraisal

Papers were appraised by the first author on their contribution to answering the research question using the Critical Appraisal Skills Programme [CASP] Qualitative Checklist ⁶⁹. Aligning with the proposed methodology for thematic synthesis ⁶², answers of “yes” to the CASP checklist beyond the screening items were considered “1 point”, generating a “hierarchy of evidence” and determining each paper’s “value”. Therefore, the CASP checklist was revised to omit the question, “how valuable is this research?”. The “hierarchy of evidence” was used to monitor the contribution of differently appraised papers to the review findings. The appraisal of a random subset of three papers was peer-reviewed by a trainee clinical psychologist.

Data Extraction and Synthesis

Data extraction and analysis were conducted in keeping with thematic synthesis methodology ⁶². All papers were entered into QSR’s NVivo 12 software. The first author selected all content under “findings/results” within each paper and novel findings or interpretations presented elsewhere (e.g. discussion).

The first author coded selected content inductively following Braun and Clarke’s principles of thematic analysis ⁷⁰. After familiarisation with the data, initial codes were generated. These codes were then grouped based on meaning to create themes, which were reviewed, re-organised and named to best represent the original data. All papers were included equally in this process, regardless of their quality appraisal score. However, the “hierarchy of evidence” was consulted to ensure final analytical themes did not predominantly rely on data from more poorly appraised papers, as in this case, themes would have been collapsed and reorganised to incorporate data from more strongly appraised papers. Analytical themes were generated by “going beyond” the individual papers’ findings to answer the review question with novel interpretations that were only possible through the collective analysis of all the papers ⁶². NVivo file available upon request.

Reflexivity

Prior to analysis the first author noted that they had no personal experiences of PAP or close relationships with anyone who had. However, repeated readings of negative experiences during the literature search had informed an expectation to read further negative experiences. The author was mindful of this when conducting the metasynthesis^{69,71}. Meanwhile, whilst the data was coded inductively and every attempt made to ensure themes “kept close” to the original data, the first author was concurrently training and working as a clinician using a biopsychosocial approach. The process and emerging themes were discussed in supervision to minimise the influence of such potential biases on the results, although it is recognised that subjective bias can never be entirely eliminated from reviews of this kind⁷².

Results

The search retrieved 6398 papers; 586 were duplicates. Titles and abstracts were reviewed against inclusion/exclusion criteria, eliminating 5,714 papers, and then a further 78 through full text review (eliminated papers largely reported on entirely quantitative research or were narrative reviews; see Figure 1). Five papers were identified through “snowballing” and “reverse snowballing”⁷³, which involved searching the reference lists of, and papers that had cited, the 20 inclusion papers retrieved from the systematic search.

Insert Figure 1 here

Table 2 summarises the 25 inclusion papers. Papers S1-S3 reported on one dataset, as did V1 and V2. Supplementary material available with paper E was included. Table 3 details the critical appraisal outcome. The papers reported on over 398 people’s experiences from across the world, but largely from Western cultures (see Table 2). Experiences were synthesised into 2898 codes and sorted into four analytical themes: Journey to PAP, Discomfort from and around PAP, Adapting to and using PAP, and Benefits from PAP. These themes are explored with supporting direct quotations from participants. Table 4 shows the papers that contributed to each theme.

Insert Tables 2-4 here

Journey to PAP – The Context Into Which Diagnosis and PAP Must Be Assimilated

People's experiences of PAP were relative to their experiences with OSA. Journeys to learning about and acquiring PAP were often difficult and long.

Difficulties Before PAP

Prior to PAP, participants' fatigue impacted their social life, relationships, mood, and functioning. Some slept poorly and disturbed bed partners. Apnoeas could be traumatic and stressful for the whole family. Similar symptoms affected participants differently but difficulties motivated participants to seek help.

Delays to Getting Treatment

A lack of public and professional awareness caused delays. Participants received misdiagnoses and misattribution of their fatigue, "The answer I got was: 'It is because you are going to an all girl school.'" (P, p.187). General Practitioners' unawareness made sleep service referrals inaccessible and only possible through specialists. Services also felt inaccessible due to long waiting times, no transparent funding routes, and existing tiredness.

Participants were also largely unaware of OSA. Snoring was embarrassing to talk about, particularly for females, and OSA was difficult to recognise without the testimony of loved ones. Some people denied having a problem due to the stigma of snoring and being overweight, not believing others or avoiding the consequences, "I don't need a doctor, I don't need to bill this to my insurance." (I, p.53). Some participants suffered for up to 30 years and were often encouraged to seek help by others.

Experiences of Assessment and Diagnosis

Some participants found their referral and assessment satisfactory. Others were too uncomfortable on their diagnostic night to sleep much, and felt staff lacked skills and confidence, which made them question their diagnosis. The OSA diagnosis was a surprise for some and experienced as threatening, "He [the MD] really scared me." (M, p.1240). Despite fears, taking on PAP was not a decision made lightly and sometimes partners influenced choices. Some people struggled with the trial and recommended that a better fitting mask and humidifier would increase comfort.

Discomfort From and Around PAP – Affects Relationships, Generating More Discomfort and Affecting PAP Use

The discomfort accompanying PAP affected multiple relationships, including the users' relationship with PAP.

Relationship With PAP

PAP was described as uncomfortable. The mask was a common complaint due to poor fit and difficulties adjusting, resulting in noisy air leaks. “The first six months or so was challenging. . . (...) it was all to do with the masks” (S1, p.375). The straps, tube and pressure were also uncomfortable; some felt hot or unable to breathe. PAP was described as a foreign body unable to synchronise with the human body, “like having a Hoover on backwards and someone's shoved the hose in your mouth.” (S3, p.8). Whilst some participants persevered, some removed PAP during the night due to discomfort and others discontinued altogether.

PAP negatively impacted users' bodies, causing dry/sore/bleeding airways, congestion, irritated eyes, aerophagia, facial sores/swelling, and back pain. Meanwhile, PAP was reported to be more uncomfortable psychologically. Fears of the machine and mask, being unable to breathe and claustrophobia were barriers. Participants also felt foolish and humiliated by PAP.

PAP was not an ideal solution, especially as participants were already struggling with OSA symptoms, “[The diagnosis] didn't bother me all that much until I got the machine” (K, p.1725). Some desperately sought alternative solutions, “If there were anything that could be done to be free of that machine, I'd do it right now” (I, p.54). Participants were reluctant to accept a lifelong solution over a cure and expressed anger at the medical profession for not developing something better.

PAP was not always felt to be worth the discomfort and was abandoned, “It's a no-win battle.” (I, p.54). Some hoped that PAP would reduce symptoms and improve quality of life. However, some did not experience this benefit, or not to the extent they had imagined or experienced from the trial. Others were conflicted; some were unsure of the benefit or their need for PAP and found reasons not to use it. Others

struggled to accept the device, experiencing a “love hate relationship” (H, p.145), or were grateful for the benefits but not happy with PAP, despite feeling they shouldn’t complain.

Relationship With Life

The addition of PAP was “extraordinarily intrusive” (B, p.233), impacting on both users and partners. Cleaning PAP was described as “a pain in the butt” (D, p.245). The necessary daily ritual was an obstacle to every day life; participants missed being able to just “go and jump into bed” (G, p.117) and fall asleep reading. The mask was annoying to apply and reapply if the user got up in the night.

Difficulties travelling with PAP restricted freedom. Users have to consider transporting PAP safely and accessing a compatible electricity supply. Some people avoided moving PAP, reducing their independence.

Lastly, PAP is expensive. For some, the cost exceeded their average monthly salary. Participants were “burdened” (J, p.274) by the expense and lack of support from insurance and public health systems. Having to consider the cost of replacing the device if necessary further reduced financial freedom.

Relationship With Self

PAP required users to adapt their identity, often towards one they stigmatised. For some, they shifted towards feeling disabled. The lifelong support was likened to a prosthesis or assistive technology, making OSA a visible disability. The lifelong nature also made participants feel old and unwell. Some knew older people who used PAP. The device resembled hospital equipment and wearing it at home felt like losing control as a submissive patient, “Makes you think I am sicker, in the ER or a nursing home” (U, p.7). Others struggled to identify as having OSA due to perceptions that OSA only affects overweight men. Women reported feeling less feminine due to snoring and PAP, “we’re supposed to be dainty when we sleep” (I, p.54).

PAP users felt unattractive in the bedroom, a place where some wished to feel desirable. Others “felt ashamed” (L, p.77) or “ridiculous” (F, p.247) and angry with themselves for needing PAP. Moreover, they

felt guilty for unconsciously removing PAP during the night, forgetting, or struggling to use it, “I tried and tried and I just couldn’t make the grade.” (H, p.145).

Relationship With Others

Users described being embarrassed and caring what others thought, especially partners, “I have to make sure that all the lights are off, (...) It makes me very, very uncomfortable” (B, p.233). Users worried PAP made them scary or unattractive, “You don’t start a relationship with somebody because of the CPAP.” (E, supplementary material). PAP impeded intimacy and co-sleep with bed partners, deterring use, “It’s had an impact on our relationship; you’ve got a frickin’ snorkel thing across your marriage bed” (I, p.54). Some users “didn’t want anybody to see” (Q, p.323) and kept PAP secret. Others shared their PAP use but experienced stigma and ridicule, feeling they had to join in the mockery of themselves to fit in.

Relationship With Sleep

Some participants felt PAP prevented sleep from being a “refuge from the burden of life” (V2, p.232). For some this was because it is “not natural to wear something to sleep” (J, p.273) and “proper sleep” (S3, p.7) could only be achieved without the restrictions of PAP. PAP also demanded a different sleeping position and sometimes interrupted rather than improved sleep, “I spend a lot of my night doing these little adjustments” (A, p.662).

Adapting To and Using PAP – A Journey Not Destination

This theme illustrates the journey of adapting to PAP and how support is crucial.

Importance of Support and Information

Reports illustrated the importance of professional and personal support to adapting to PAP. The benefit of contact with the PAP community was similar across different opportunities. Participants felt part of an encouraging community whilst they learned from others’ experiences and had their difficulties normalised. Experienced users wished to help others, “I would really like to be part of something that might prevent other people from going through what I have” (P, p.189) and did so through being a role model,

promoting PAP, and encouraging self-advocacy, “Don’t feel that it’s your fault. Get it straightened out” (G, p.118).

Some participants found support came from people around them. Working “together as a couple” (U, p.5) to integrate PAP, absence of a negative reaction, and reassurance was described as helpful. Others described a lack of encouragement, assistance and support as being barriers to use, alongside conflicted priorities and partner scepticism, “It’s not easy to counter the effect of your wife saying, ‘[CPAP] is not going to work for you!’” (B, p.233).

Helpful professional relationships involved trust, consideration and dependability. Participants stressed the benefits of a straightforward accessible process, ongoing support, sufficient information, and “the possibility to try the CPAP at the hospital.” (E, supplementary data). This support provided relief and facilitated acceptance and integration of PAP. Information on both OSA and PAP was reported to be powerful in equipping people, “gave me a strong motivation and I think I was comfortable and well prepared to meet all possible problems.” (D, p.108).

Individualised care and sufficient provision were commonly lacking. Participants struggled to use PAP without information on OSA, PAP and how to access support. Follow up support was often unavailable or inaccessible due to working hours and staff availability. Some found providers unknowledgeable, which led some to view PAP as “just another way for the medical establishment to make money.” (P, 188).

“When I first went to get the machine, unfortunately it’s a salesman talking to you.... So I had to sit and listen to an hourlong sales spiel.... I’m going—okay just tell me how to use the machine.... I didn’t even get a manual. I called a few times, and they had to call you back because they are salespeople; you get lost and overlooked.” (F, 246)

Meanwhile, some insurance companies were unwilling to pay for PAP creating the impression that some people “just have apnoeas and die” (H, p.143). Participants felt alone and unable to request help. Users recommended that services be personalised and provide more information, coordinated care, and a chance to try different equipment. Follow up support was deemed necessary for empowerment and assistance with

inevitable difficulties, “I wanted to know how I was doing. (...) why doesn’t somebody call me and say, ‘You’re doing pretty good, lady. You’re keeping this thing on for eight hours.’” (L, p.78).

Effort Necessary to Adapt

Adapting to PAP was described as “trial and error” (S1, p.375). Trialling the benefits, creative problem solving and “learning by doing” (M, p.1240) occurred in the absence of professional support. Some users sought additional information on PAP through online research, support groups and family and friends. Users became experts in their own care by learning how to maintain, adapt and repair their machines, monitor their OSA and self-advocate, “I am battling the insurance company because they are saying I shouldn’t have one [CPAP].” (F, p.247).

PAP required compromise. The home environment was adapted; from buying a bedside table to drilling a hole in the wall so the machine could live in the next room. Users’ bodies also had to compromise: “I trained myself to sleep on my back and hold the hose with my left hand so it doesn’t move.” (G, p.118). Meanwhile, partners had to compromise alongside users, “This Hoover-head made the wrong choice buying a bed. (...) We literally wake up sore in the morning!”. (O, p.106).

Users also had to “stay with it.”(G, p.118). Perseverance was important to grow accustomed, time is required to establish PAP as routine, “Persevere for a while, and then you’ll get used to it and then you won’t ever want to be without it.” (S3, p.8).

Attitude, Belief and Context

PAP use was initially influenced by mindset but then by the journey of adaptation. Acceptance seemed key to use, mostly through accepting the compromise, “hideous, but you feel more hideous if you don’t use it.” (S1, p.375). Some accepted the compromise through “relief that we were finally going to get something done” (C, p.226). Others were desperate and willing to do and “pay for anything that would help.” (A, p.664). Some reported to “accept it [the CPAP] with love.” (V2, p.230) and encouraged others’ acceptance by telling them about PAP, “I’m not ashamed anymore, (...) I tell as many people as I can” (C, p.226).

Humour was depicted to buffer some discomfort, “My grandchildren have seen me in mine, and I’m not the slightest bit worried...I gave them very clear instructions about ‘grandpa’s elephant nose!’” (H, p.145). This buffering perhaps resembles acceptance, but it might be unhelpful for some, “he tries to make light by cracking jokes, but it doesn’t necessarily make me feel any better” (S2, p.85). Avoidance over acceptance seemed a barrier to use. Some participants felt their OSA wasn’t as bad as others’, that losing weight would be better than PAP, or were sceptical about PAP’s importance, “you just think of it as a snoring thing. You don’t think of it as, I’ve got cancer and I’m going to die” (Q, p.322).

Some believed in PAP, “I was sure that it should work, and it does.” (E, supplementary data) and others were committed regardless, “there was no way around it, it was just getting on with it” (M, p.1240). Many used PAP as protection from negative social, vocational or physical health consequences, such as losing their driver’s license. Others were not motivated for themselves but wanted to benefit others, “If you love her [the partner], use it.” (U, p.7). Positivity, confidence, and the users’ belief in their abilities also helped PAP use. Ultimately, context influenced users’ motivations and attitudes, which were susceptible to change.

PAP Use a Journey Not Destination

Participants portrayed PAP use as an evolving relationship, not an end to suffering. Most papers reported all early experiences to be difficult, regardless of outcome. PAP use was a battle not always won. Some participants had managed to grow accustomed to PAP despite challenges, and some were still struggling. Even after the battle, PAP use was fluid not fixed; even committed users reported exceptions, “If I am going someplace special, I will just not wear it that night.” (F, p.247). Others seemed uncertain about their commitment and deciding daily felt more comfortable than lifelong commitment. Few people were fully satisfied with PAP. Users described continually evaluating their compromise and potentially changing their minds. Non-users also reported ambivalence, with some reporting big fluctuations in their usage over time.

Meanwhile, PAP experience changed over time. Small changes for the user or machine affected the relationship. Changes in PAP due to repair or replacement required a process of readjustment. Meanwhile, “so many different issues” (H, p.145) affected sleep. Changes in peer group opinion and other health conditions also impacted use. Assessment of ongoing needs was indicated; the benefits of PAP receded for some whilst others were unsure of their continued need for PAP after losing weight.

However, PAP was sold as a destination rather than a journey. Device settings were fixed and not reviewed. As bodies are not fixed entities, users tried to adjust their equipment to fluctuating needs and struggled to use devices that no longer helped. Usage was monitored but not users’ experience or mental wellbeing, “I have to send it [compliance card] to make sure you use it like a big brother; I don’t like being watched.” (F, p.247). Even the information provided portrayed a ‘one size fits all’ solution:

“there wasn’t a lot of personal stuff in there, like people that have actually used machines. So when I was on the net I was just basically looking at people’s experiences with the machines and their own journeys with it.” (Q, p.322)

Participants proved largely autonomous in their care, wished to be more involved in treatment decisions and wanted to work towards personal goals rather than optimal usage, “We [people with OSA] cannot be pigeonholed. Each of us has to be looked at as an individual.” (P. p.191).

Desired Outcomes

Some participants described PAP becoming “a ritual and a new normality, almost like brushing your teeth” (M, p.1240). This seemed a comfortable position, suggesting some users may reach a desirable destination. Some reported, “there aren’t really any difficulties with the machine. It’s really too easy.” (B, p.233). This report’s contrast to others highlights how influential context is, and perhaps how an easy PAP experience is expected, “I don’t understand anybody that doesn’t do good on it because it makes you feel so much better.” (K, p.1726).

Benefits From PAP – Engender Motivation and Positive Relationships With PAP

Most papers reported benefits that motivated use and facilitated a positive relationship with PAP.

PAP Effects on OSA

PAP relieved snoring, apnoeas and daytime sleepiness, bringing OSA “under control” (S1, p.374). Participants described a better quality of sleep that was more satisfying and refreshing for them and their partners, “Now in the mornings, it’s so much easier to get up” (L, p.77). Some hadn’t fully appreciated their symptoms before and noticed a real difference when they didn’t use PAP. Users felt more alert, “I’m safe on the road now” (Q, p.323) and energetic which helped them reduce lifestyle contributors to OSA, “I’m in the gym, losing weight” (C, p.225).

PAP Effects on Wider Life

The benefits generated a “better quality of life” (U, p.5). It was “nice to be able to go to places and not have to worry about falling asleep.” (B, p.233). Physical and psychological wellbeing improved. Participants reported feeling less irritable and anxious and more “able to relax” (T, p.169). Some felt PAP had returned them to their former selves. PAP reportedly “helps the whole house” (C, p.225) through improving sleep, mood and relationship quality. Some couples were able to sleep in the same room again.

Relationship of Improvements to PAP Use

Benefits motivated use, “you get a much better life.” (M, p.1240). Some experienced immediate and notable differences, “I haven’t felt this good in years. It was like night and day; it saved my life.” (G, 117). Maintaining PAP use was harder alongside subtle improvements, unless these matched expectations, “I wanted to keep trying because he had told me it might take a while, and then I did notice gradual changes.” (F, p.246).

Bonded to PAP

Different bonds motivated PAP use. Some reported to “depend on it” (J, p.276) and would take it when travelling. PAP was trusted to keep users well and provided a sense of hope, “I feel so secure with it” (C, p.225). Others found PAP “soothing” (K, p.1728) and felt thankful for the benefits.

Discussion

The findings highlight the applicability of a biopsychosocial understanding to PAP use and the importance of individualising treatment to suit the user. The theme “Journey to PAP” depicts biological influences. Participants largely struggled with OSA symptoms but had difficulty obtaining the diagnosis or wouldn’t seek help; consistent with findings of an average of up to ten years between symptom onset and diagnosis ^{74,75}. Limited public and professional awareness presented a barrier. Findings suggest symptom severity influences PAP use more than OSA severity ²⁵. Perhaps people experiencing greater symptoms are more motivated to overcome barriers to acquire and use PAP.

The theme “Discomfort from and around PAP” emerged from prevalent reports that PAP generates psychological as well as physical discomfort ^{41,42}, impacting use. PAP use required an often-uncomfortable shift in identity, generating stigma from individual and cultural prejudices, highlighting the importance of understanding the personal experience of PAP. Older age is associated with PAP use ⁷⁶, potentially reflecting higher acceptability of lifelong treatment in later life. The stigma experienced by PAP users from themselves and others is not well documented ^{77,78} and warrants further research as stigma is known to impact other treatments ^{79–81}.

People who have not tried PAP report wanting to avoid reliance ⁸². However, users depicted dependence as a positive bond within “Benefits of PAP”, highlighting the role of psychological factors such as attitude and belief within “Adapting to and using PAP”. Early attachment patterns may influence relationships with healthcare services ⁸³ and may similarly affect relationships with PAP, perhaps explaining why dependence is soothing for some and avoided by others. Such psychological influences on PAP use are conceivably complex and require further research.

Benefits were infrequently reported and highlighted the influence of expectation. Some experienced drastic changes from PAP use, which outweighed any discomfort experienced. It is possible that these ideal yet infrequent experiences have informed expectations. Subtle changes were less motivating, highlighting the importance of realistic expectations and ongoing professional input.

The users' social context was also reported to affect PAP use. Support was overwhelmingly cited as important. Most accounts suggested that services provided little initial and ongoing support, meaning PAP use relied on the individual or their personal networks. Information on OSA and PAP emerged as crucial. Research suggests that professionals underestimate the importance of information and overestimate the impact of side effects⁸⁴. These findings suggest that professionals may overemphasise discomfort at the expense of other information, potentially increasing user experience of discomfort through confirmation bias⁸⁵. Moreover, it may reflect professional beliefs, similar to the current findings of user frustration, that PAP is not an ideal solution and warrants further research.

Some included studies enabled participants to connect with other users. Group sessions were recommended as helpful whilst experienced users wanted to help others use PAP. Connecting users is an inexpensive way for services to provide ongoing support. Moreover, the benefit reported of involving people around the user in PAP treatment, particularly considering their role in initially recognising OSA, supports other findings^{65,86}. Again, it is a low-cost solution to utilise existing support networks. Meanwhile, it may provide services the opportunity to understand and mitigate personal relationship difficulties that the current findings, alongside others, suggest hinder PAP use^{34,87}.

However, services should not rely on personal networks to support users. Although personal support was largely reported as readily available, participants' PAP usage was still reported as suboptimal, suggesting sufficient professional support is also imperative. The findings also suggested that PAP is sold to users as a destination whilst user experiences conveyed a lifelong journey that is especially difficult in the early stages. To assist this journey, participants described needing ongoing support and wanting to share decision-making, goals and monitoring around their treatment. The focus on objective PAP use was experienced as impersonal and unhelpful.

The needs highlighted here match The World Health Organisation's 2003 recommendations on working collaboratively with people and their families to support long-term treatment use⁸⁸. The recommendations detail that users should not be blamed for non-optimal use and that service level factors,

such as absent personalised holistic ongoing support, have a major effect. However, the PAP literature continues the user blaming narrative, despite the emergence of research discrediting focus on objective measures of use⁸⁹⁻⁹¹. PAP use is considered an important challenge to sleep medicine and the utility of OSA as a diagnosis, making investment towards supporting PAP use crucial⁹².

Given the reported role of acceptance, it is also thought that Acceptance and Commitment Therapy (ACT)⁹³ principles may help contextualise PAP use as supportive of user values. Whilst not the only intervention that can facilitate acceptance, ACT is an evidence-based biopsychosocial approach used to support management of other long-term conditions⁹⁴. However, as PAP use is an individual, context dependent, lifelong journey, no supportive or educational interventions will likely be effective for all PAP users at once. Instead, users may benefit from a range of support across their lifetime. Therefore, PAP services should expand the information and support available, making use of a range of evidence-based interventions^{52-55,95,96} and facilitate collaborative decisions, goals and monitoring between professionals, users and their networks⁹⁷.

Despite reflexive efforts to reduce bias within the findings and interpretations, all systematic reviews contain bias⁷². Seven papers contained translated experiences, increasing opportunities for misunderstanding and misrepresentation. Additionally, some findings may be country specific. Many papers had only recruited current PAP users, potentially reducing the inclusion of more difficult experiences of PAP. Meanwhile, the current review excluded narratives of significant others. Based on the reported role of others in recognising OSA and supporting PAP use, future research is recommended to include these perspectives to corroborate and enhance the current understandings. Future research is also necessary to build on the current findings, particularly the 'thinner' themes.

This metasynthesis hoped to address the absence of user's voices within the PAP literature. The findings support a biopsychosocial conceptualisation of PAP use and highlight the limitations of the literature's emphasis on individual factors. Collaborative, person-centred and holistic ongoing support is needed to improve PAP use.

References

1. Gibson GJ. Obstructive sleep apnoea syndrome: underestimated and undertreated. *British Medical Bulletin*. 2004;72(1):49-64. doi:10.1093/bmb/ldh044
2. Young T, Palta M, Dempsey J, Skatrud J, Weber S, Badr S. The occurrence of sleep-disordered breathing among middle-aged adults. *New England Journal of Medicine*. 1993;328(17):1230-1235. doi:10.1056/NEJM199304293281704
3. Franklin KA, Lindberg E. Obstructive sleep apnea is a common disorder in the population—a review on the epidemiology of sleep apnea. *J Thorac Dis*. 2015;7(8):1311-1322. doi:10.3978/j.issn.2072-1439.2015.06.11
4. Senaratna CV, Perret JL, Lodge CJ, et al. Prevalence of obstructive sleep apnea in the general population: A systematic review. *Sleep Medicine Reviews*. 2017;34:70-81. doi:10.1016/j.smr.2016.07.002
5. Shamsuzzaman ASM, Gersh BJ, Somers VK. Obstructive sleep apnea: implications for cardiac and vascular disease. *JAMA*. 2003;290(14):1906-1914. doi:10.1001/jama.290.14.1906
6. Rajan P, Greenberg H. Obstructive sleep apnea as a risk factor for type 2 diabetes mellitus. *Nat Sci Sleep*. 2015;7:113-125. doi:10.2147/NSS.S90835
7. Stubbs B, Vancampfort D, Veronese N, et al. The prevalence and predictors of obstructive sleep apnea in major depressive disorder, bipolar disorder and schizophrenia: A systematic review and meta-analysis. *Journal of Affective Disorders*. 2016;197:259-267. doi:10.1016/j.jad.2016.02.060
8. Beebe DW, Gozal D. Obstructive sleep apnea and the prefrontal cortex: towards a comprehensive model linking nocturnal upper airway obstruction to daytime cognitive and behavioral deficits. *Journal of Sleep Research*. 2002;11(1):1-16. doi:10.1046/j.1365-2869.2002.00289.x
9. Reishtein JL, Pack AI, Maislin G, et al. Sleepiness and relationships in obstructive sleep apnea. *Issues in Mental Health Nursing*. 2006;27(3):319-330. doi:10.1080/01612840500503047
10. Shastri A, Bangar S, Holmes J. Obstructive sleep apnoea and dementia: is there a link? *International Journal of Geriatric Psychiatry*. 2016;31(4):400-405. doi:10.1002/gps.4345
11. Tregear S, Reston J, Schoelles K, Phillips B. Obstructive sleep apnea and risk of motor vehicle crash: systematic review and meta-analysis. *J Clin Sleep Med*. 2009;5(6):573-581. doi:https://doi.org/10.5664/jcsm.27662
12. McArdle N, Kingshott R, Engleman H, Mackay T, Douglas N. Partners of patients with sleep apnoea/hypopnoea syndrome: effect of CPAP treatment on sleep quality and quality of life. *Thorax*. 2001;56(7):513-518. doi:10.1136/thorax.56.7.513
13. Costa LE, Uchôa CHG, Harmon RR, Bortolotto LA, Lorenzi-Filho G, Drager LF. Potential underdiagnosis of obstructive sleep apnoea in the cardiology outpatient setting. *Heart*. 2015;101(16):1288-1292. doi:10.1136/heartjnl-2014-307276

14. Chung F, Abdullah HR, Liao P. STOP-Bang Questionnaire: a practical approach to screen for obstructive sleep apnea. *Chest*. 2016;149(3):631-638. doi:10.1378/chest.15-0903
15. Tarasiuk A, Reuveni H. The economic impact of obstructive sleep apnea. *Current Opinion in Pulmonary Medicine*. 2013;19(6):639-644. doi:10.1097/MCP.0b013e3283659e1e
16. Knauert M, Naik S, Gillespie MB, Kryger M. Clinical consequences and economic costs of untreated obstructive sleep apnea syndrome. *World Journal of Otorhinolaryngology-Head and Neck Surgery*. 2015;1(1):17-27. doi:10.1016/j.wjorl.2015.08.001
17. Qaseem A, Holty J-EC, Owens DK, Dallas P. Management of obstructive sleep apnea in adults: a clinical practice guideline from the American College of Physicians. *Ann Intern Med*. September 2013. doi:10.7326/0003-4819-159-7-201310010-00704
18. Engleman HM, McDonald JP, Graham D, et al. Randomized crossover trial of two treatments for sleep apnea/hypopnea syndrome: continuous positive airway pressure and mandibular repositioning splint. *Am J Respir Crit Care Med*. 2002;166(6):855-859. doi:10.1164/rccm.2109023
19. Giles TL, Lasserson TJ, Smith B, White J, Wright JJ, Cates CJ. Continuous positive airways pressure for obstructive sleep apnoea in adults. *Cochrane Database of Systematic Reviews*. 2006;(1). doi:10.1002/14651858.CD001106.pub2
20. Weatherly HLA, Griffin SC, Mc Daid C, et al. An economic analysis of continuous positive airway pressure for the treatment of obstructive sleep apnea-hypopnea syndrome. *International Journal of Technology Assessment in Health Care; Cambridge*. 2009;25(1):26-34. doi:http://dx.doi.org/10.1017/S0266462309090047
21. Kakkar RK, Berry RB. Positive airway pressure treatment for obstructive sleep apnea. *Chest*. 2007;132(3):1057-1072. doi:10.1378/chest.06-2432
22. Campos-Rodriguez F, Peña-Griñan N, Reyes-Nuñez N, et al. Mortality in obstructive sleep apnea-hypopnea patients treated with positive airway pressure. *Chest*. 2005;128(2):624-633. doi:10.1378/chest.128.2.624
23. Drager LF, Bortolotto LA, Figueiredo AC, Krieger EM, Lorenzi-Filho G. Effects of continuous positive airway pressure on early signs of atherosclerosis in obstructive sleep apnea. *Am J Respir Crit Care Med*. 2007;176(7):706-712. doi:10.1164/rccm.200703-5000C
24. Pichel F, Zamarrón C, Magán F, del Campo F, Alvarez-Sala R, Rodríguez Suarez JR. Health-related quality of life in patients with obstructive sleep apnea: effects of long-term positive airway pressure treatment. *Respiratory Medicine*. 2004;98(10):968-976. doi:10.1016/j.rmed.2004.03.009
25. Weaver TE, Grunstein RR. Adherence to Continuous Positive Airway Pressure Therapy: The Challenge to Effective Treatment. *Proceedings of the American Thoracic Society*. 2008;5(2):173-178. doi:10.1513/pats.200708-119MG

26. Richard W, Venker J, den Herder C, et al. Acceptance and long-term compliance of nCPAP in obstructive sleep apnea. *Eur Arch Otorhinolaryngol*. 2007;264(9):1081-1086. doi:10.1007/s00405-007-0311-3
27. Palm A, Midgren B, Theorell-Haglöw J, et al. Factors influencing adherence to continuous positive airway pressure treatment in obstructive sleep apnea and mortality associated with treatment failure - a national registry-based cohort study. *Sleep Med*. 2018;51:85-91. doi:10.1016/j.sleep.2018.07.007
28. Kohler M, Smith D, Tippet V, Stradling JR. Predictors of long-term compliance with continuous positive airway pressure. *Thorax*. 2010;65(9):829-832. doi:10.1136/thx.2010.135848
29. Wild MR, Engleman HM, Douglas NJ, Espie CA. Can psychological factors help us to determine adherence to CPAP? A prospective study. *European Respiratory Journal*. 2004;24(3):461-465. doi:10.1183/09031936.04.00114603
30. Olsen S, Smith S, Oei T, Douglas J. Health belief model predicts adherence to CPAP before experience with CPAP. *European Respiratory Journal*. 2008;32(3):710-717. doi:10.1183/09031936.00127507
31. Stepnowsky CJ, Bardwell WA, Moore PJ, Ancoli-Israel S, Dimsdale JE. Psychologic correlates of compliance with continuous positive airway pressure. *Sleep*. 2002;25(7):758-762. doi:10.1093/sleep/25.7.758
32. Law M, Naughton M, Ho S, Roebuck T, Dabscheck E. Depression may reduce adherence during CPAP titration trial. *Journal of Clinical Sleep Medicine*. 2014;10(02):163-169. doi:10.5664/jcsm.3444
33. Aloia MS, Arnedt JT, Stepnowsky C, Hecht J, Borrelli B. Predicting treatment adherence in obstructive sleep apnea using principles of behavior change. *J Clin Sleep Med*. 2005;1(4):346-353. doi:https://doi.org/10.5664/jcsm.26359
34. Baron KG, Smith TW, Berg CA, Czajkowski LA, Gunn H, Jones CR. Spousal involvement in CPAP adherence among patients with obstructive sleep apnea. *Sleep Breath*. 2011;15(3):525-534. doi:10.1007/s11325-010-0374-z
35. Billings ME, Auckley D, Benca R, et al. Race and residential socioeconomic status as predictors of CPAP adherence. *Sleep*. 2011;34(12):1653-1658. doi:10.5665/sleep.1428
36. Bakker JP, O'Keefe KM, Neill AM, Campbell AJ. Ethnic disparities in CPAP adherence in New Zealand: effects of socioeconomic status, health literacy and self-efficacy. *Sleep*. 2011;34(11):1595-1603. doi:10.5665/sleep.1404
37. Platt AB, Field SH, Asch DA, et al. Neighborhood of residence is associated with daily adherence to CPAP therapy. *Sleep*. 2009;32(6):799-806. doi:10.1093/sleep/32.6.799
38. Campbell A, Neill A, Lory R. Ethnicity and socioeconomic status predict initial continuous positive airway pressure compliance in New Zealand adults with obstructive sleep apnoea. *Internal Medicine Journal*. 2012;42(6):e95-e101. doi:10.1111/j.1445-5994.2010.02360.x

39. Gagnadoux F, Le Vaillant M, Goupil F, et al. Influence of marital status and employment status on long-term adherence with continuous positive airway pressure in sleep apnea patients. *PLoS One*. 2011;6(8). doi:10.1371/journal.pone.0022503
40. Luyster FS. Impact of obstructive sleep apnea and its treatments on partners: a literature review. *Journal of Clinical Sleep Medicine*. 2017;13(03):467-477. doi:10.5664/jcsm.6504
41. Ulander M, Johansson MS, Ewaldh AE, Svanborg E, Broström A. Side effects to continuous positive airway pressure treatment for obstructive sleep apnoea: changes over time and association to adherence. *Sleep Breath*. 2014;18(4):799-807. doi:10.1007/s11325-014-0945-5
42. Broström A, Årestedt KF, Nilsen P, Strömberg A, Ulander M, Svanborg E. The side-effects to CPAP treatment inventory: the development and initial validation of a new tool for the measurement of side-effects to CPAP treatment: The side-effects to CPAP treatment inventory. *Journal of Sleep Research*. 2010;19(4):603-611. doi:10.1111/j.1365-2869.2010.00825.x
43. Leggett MK. A brief review of claustrophobia and continuous positive airway pressure (CPAP) therapy for sleep apnea. *Journal of Sleep Medicine & Disorders*. 2016;3(2):1-4.
44. Engleman HM, Wild MR. Improving CPAP use by patients with the sleep apnoea/hypopnoea syndrome (SAHS). *Sleep Medicine Reviews*. 2003;7(1):81-99. doi:10.1053/smr.2001.0197
45. Olsen S, Smith S, Oei T. Adherence to continuous positive airway pressure therapy in obstructive sleep apnoea sufferers: A theoretical approach to treatment adherence and intervention. *Clinical Psychology Review*. 2008;28(8):1355-1371. doi:10.1016/j.cpr.2008.07.004
46. Stepnowsky CJ, Moore P. Letter to the editors. *Sleep Medicine Reviews*. 2003;7(5):445-446. doi:10.1053/smr.2002.0289
47. Crawford MR, Espie CA, Bartlett DJ, Grunstein RR. Integrating psychology and medicine in CPAP adherence – new concepts? *Sleep Medicine Reviews*. 2014;18(2):123-139. doi:10.1016/j.smr.2013.03.002
48. Hilbert J, Yaggi HK. Patient-centered care in obstructive sleep apnea: a vision for the future. *Sleep Medicine Reviews*. 2018;37:138-147. doi:10.1016/j.smr.2017.02.004
49. Lettieri CJ, Williams SG, Collen JF, Wickwire EM. Treatment of obstructive sleep apnea: achieving adherence to positive airway pressure treatment and dealing with complications. *Sleep Medicine Clinics*. 2017;12(4):551-564. doi:10.1016/j.jsmc.2017.07.005
50. Wickwire EM, Lettieri CJ, Cairns AA, Collop NA. Maximizing positive airway pressure adherence in adults. *Chest*. 2013;144(2):680-693. doi:10.1378/chest.12-2681
51. Russell T. Enhancing adherence to positive airway pressure therapy for sleep disordered breathing. *Semin Respir Crit Care Med*. 2014;35(05):604-612. doi:10.1055/s-0034-1390070
52. Wozniak D, Lasserson T, Smith I. Educational, supportive and behavioural interventions to improve usage of continuous positive airway pressure machines in adults with obstructive sleep apnoea. *Cochrane Database of Systematic Reviews*. 2014;(1). doi:10.1002/14651858.CD007736.pub2

53. Dickerson SS, Jungquist C, TenBrock E, et al. Feasibility testing of a self-management program book to improve adherence to PAP in persons newly diagnosed with sleep apnea. *Behavioral Sleep Medicine*. 2018;16(5):413-426. doi:10.1080/15402002.2016.1228644
54. Jurado-Gamez B, Bardwell WA, Cordova-Pacheco LJ, García-Amores M, Feu-Collado N, Buela-Casal G. A basic intervention improves CPAP adherence in sleep apnoea patients: a controlled trial. *Sleep Breath*. 2015;19(2):509-514. doi:10.1007/s11325-014-1038-1
55. Soares Pires F, Drummond M, Marinho A, et al. Effectiveness of a group education session on adherence with APAP in obstructive sleep apnea—a randomized controlled study. *Sleep Breath*. 2013;17(3):993-1001. doi:10.1007/s11325-012-0789-9
56. Bakker JP, Weaver TE, Parthasarathy S, Aloia MS. Adherence to CPAP: what should we be aiming for, and how can we get there? *Chest*. 2019;155(6):1272-1287. doi:10.1016/j.chest.2019.01.012
57. Ward K, Hoare KJ, Gott M. What is known about the experiences of using CPAP for OSA from the users' perspective? A systematic integrative literature review. *Sleep Medicine Reviews*. 2014;18(4):357-366. doi:10.1016/j.smrv.2014.01.001
58. Ring NA, Ritchie K, Mandava L, Jepson R. A guide to synthesising qualitative research for researchers undertaking health technology assessments and systematic reviews. *NHS Quality Improvement Scotland*. 2011. <http://hdl.handle.net/1893/3205>. Accessed February 27, 2020.
59. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Medicine*. 2009;6(7):6. doi:<https://doi.org/10.1371/journal.pmed.1000097>
60. Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol*. 2012;12(1):181. doi:10.1186/1471-2288-12-181
61. Thorne S, Jensen L, Kearney MH, Noblit G, Sandelowski M. Qualitative Metasynthesis: Reflections on Methodological Orientation and Ideological Agenda. *Qual Health Res*. 2004;14(10):1342-1365. doi:10.1177/1049732304269888
62. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol*. 2008;8(1):45. doi:10.1186/1471-2288-8-45
63. Wicks AC, Freeman RE. Organization studies and the new pragmatism: positivism, anti-positivism, and the search for ethics. *Organization Science*. 1998;9(2):123-140. doi:10.1287/orsc.9.2.123
64. Butler A, Hall H, Copnell B. A guide to writing a qualitative systematic review protocol to enhance evidence-based practice in nursing and health care. *Worldviews on Evidence-Based Nursing*. 2016;13(3):241-249. doi:10.1111/wvn.12134
65. Elfström M, Karlsson S, Nilsen P, Fridlund B, Svanborg E, Broström A. Decisive situations affecting partners' support to continuous positive airway pressure-treated patients with obstructive sleep apnea syndrome: a critical incident technique analysis of the initial treatment phase. *Journal of Cardiovascular Nursing*. 2012;27(3):228-239. doi:10.1097/JCN.0b013e3182189c34

66. Alebraheem Z, Toulany A, Baker A, Christian J, Narang I. Facilitators and barriers to positive airway pressure adherence for adolescents. A qualitative study. *Annals ATS*. 2018;15(1):83-88. doi:10.1513/AnnalsATS.201706-4720C
67. Smith C, Mayer L, Metsker C, et al. Continuous positive airway pressure: patients' and caregivers' learning needs and barriers to use. *Heart & lung : the journal of critical care*. 1998;27(2):99-108. doi:10.1016/s0147-9563(98)90017-6
68. Thomas DR. A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation*. 2006;27(2):237-246. doi:10.1177/1098214005283748
69. Critical Appraisal Skills Programme. CASP Qualitative Checklist. <https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf>. Published 2018. Accessed March 3, 2020.
70. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77-101. doi:10.1191/1478088706qp063oa
71. Noyes J, Booth A, Flemming K, et al. Cochrane Qualitative and Implementation Methods Group guidance series—paper 3: methods for assessing methodological limitations, data extraction and synthesis, and confidence in synthesized qualitative findings. *Journal of Clinical Epidemiology*. 2018;97:49-58. doi:10.1016/j.jclinepi.2017.06.020
72. MacLure M. 'Clarity bordering on stupidity': where's the quality in systematic review? *Journal of Education Policy*. 2005;20(4):393-416. doi:10.1080/02680930500131801
73. Sayers A. Tips and tricks in performing a systematic review. *Br J Gen Pract*. 2007;57(542):759. doi:<https://doi.org/10.3399/bjgp08X277168>
74. Guilleminault C. Upper airway sleep-disordered breathing in women. *Ann Intern Med*. 1995;122(7):493. doi:10.7326/0003-4819-122-7-199504010-00003
75. Rahaghi F, Basner RC. Delayed diagnosis of obstructive sleep apnea: don't ask, don't tell. *Sleep Breath*. 1999;3(4):119-124. doi:10.1055/s-1999-22080
76. May AM, Gharibeh T, Wang L, et al. CPAP adherence predictors in a randomized trial of moderate-to-severe OSA enriched with women and minorities. *Chest*. 2018;154(3):567-578. doi:10.1016/j.chest.2018.04.010
77. Ward K, Gott M, Hoare K. Making choices about CPAP: findings from a grounded theory study about living with CPAP. *Collegian*. 2017;24(4):371-379. doi:10.1016/j.colegn.2016.08.002
78. Shapiro GK, Shapiro CM. Factors that influence CPAP adherence: an overview. *Sleep Breath*. 2010;14(4):323-335. doi:10.1007/s11325-010-0391-y
79. Katz IT, Ryu AE, Onuegbu AG, et al. Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *Journal of the International AIDS Society*. 2013;16(3S2):18640. doi:10.7448/IAS.16.3.18640

80. Jennings KS, Cheung JH, Britt TW, et al. How are perceived stigma, self-stigma, and self-reliance related to treatment-seeking? A three-path model. *Psychiatric Rehabilitation Journal*. 2015;38(2):109-116. doi:10.1037/prj0000138
81. Keyes KM, Hatzenbuehler ML, McLaughlin KA, et al. Stigma and treatment for alcohol disorders in the United States. *American Journal of Epidemiology*. 2010;172(12):1364-1372. doi:10.1093/aje/kwq304
82. Zarhin D. "I don't want to see myself as a disabled person": continuous positive airway pressure devices and the emergence of (dis)ability as subjectivity. *Science, Technology, & Human Values*. 2018;43(2):224-246. doi:10.1177/0162243917711006
83. Hunter JJ, Maunder RG. Using attachment theory to understand illness behavior. *General Hospital Psychiatry*. 2001;23(4):177-182. doi:10.1016/S0163-8343(01)00141-4
84. Broström A, Strömberg A, Ulander M, Fridlund B, Mårtensson J, Svanborg E. Perceived informational needs, side-effects and their consequences on adherence—A comparison between CPAP treated patients with OSAS and healthcare personnel. *Patient Education and Counseling*. 2009;74(2):228-235. doi:10.1016/j.pec.2008.08.012
85. Glick M. Believing is seeing: confirmation bias. *The Journal of the American Dental Association*. 2017;148(3):131-132. doi:10.1016/j.adaj.2017.01.009
86. Ye L, Malhotra A, Kayser K, et al. Spousal involvement and CPAP adherence: a dyadic perspective. *Sleep Med Rev*. 2015;0:67-74. doi:10.1016/j.smr.2014.04.005
87. Baron KG, Smith TW, Czajkowski LA, Gunn HE, Jones CR. Relationship quality and CPAP adherence in patients with obstructive sleep apnea. *Behavioral Sleep Medicine*. 2009;7(1):22-36. doi:10.1080/15402000802577751
88. World Health Organization, ed. *Adherence to Long-Term Therapies: Evidence for Action*. Geneva: World Health Organization; 2003. https://www.who.int/chp/knowledge/publications/adherence_full_report.pdf?ua=1.
89. Stepnowsky CJ, Moore PJ. Nasal CPAP treatment for obstructive sleep apnea: developing a new perspective on dosing strategies and compliance. *Journal of Psychosomatic Research*. 2003;54(6):599-605. doi:10.1016/S0022-3999(03)00038-2
90. Billings ME, Rosen CL, Wang R, et al. Is the relationship between race and continuous positive airway pressure adherence mediated by sleep duration? *Sleep*. 2013;34(12):1653-1658. doi:10.5665/sleep.2376
91. Sawyer AM. Building a scientific basis to address adherence disparities among adults with CPAP-treated obstructive sleep apnea. *Sleep*. 2013;36(2):163-164. doi:10.5665/sleep.2360
92. Zarhin D, Oksenberg A. Ambivalent adherence and nonadherence to continuous positive airway pressure devices: a qualitative study. *Journal of Clinical Sleep Medicine*. 2017;13(12):1375-1384. doi:10.5664/jcsm.6828
93. Hayes S, Strosahl K, Wilson KG. *Acceptance and Commitment Therapy: An Experiential Approach to Behavior Change*. New York: Guilford Press; 1999.

94. Graham CD, Gouick J, Krahé C, Gillanders D. A systematic review of the use of Acceptance and Commitment Therapy (ACT) in chronic disease and long-term conditions. *Clinical Psychology Review*. 2016;46:46-58. doi:10.1016/j.cpr.2016.04.009
95. Stepnowsky C, Edwards C, Zamora T, Barker R, Agha Z. Patient perspective on use of an interactive website for sleep apnea. *International Journal of Telemedicine and Applications*. 2013;2013:1-10. doi:10.1155/2013/239382
96. Stepnowsky CJ, Palau JJ, Gifford AL, Ancoli-Israel S. A self-management approach to improving continuous positive airway pressure adherence and outcomes. *Behavioral Sleep Medicine*. 2007;5(2):131-146. doi:10.1080/15402000701190622
97. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Education and Counseling*. 2006;60(3):301-312. doi:10.1016/j.pec.2005.06.010
98. Almeida FR, Henrich N, Marra C, et al. Patient preferences and experiences of CPAP and oral appliances for the treatment of obstructive sleep apnea: a qualitative analysis. *Sleep Breath*. 2013;17(2):659-666. doi:10.1007/s11325-012-0739-6
99. Ayow TM, Paquet F, Dallaire J, Purden M, Champagne KA. Factors influencing the use and nonuse of continuous positive airway pressure therapy: a comparative case study. *Rehabilitation Nursing*. 2009;34(6):230-236. doi:10.1002/j.2048-7940.2009.tb00255.x
100. Bakker J, O'Keeffe K, Neill A, Campbell A. Continuous positive airway pressure treatment for obstructive sleep apnoea: Maori, Pacific and New Zealand European experiences. *J Prim Health Care*. 2014;6(3):221-228. doi:https://doi.org/10.1071/HC14221
101. Broström A, Johansson P, Albers J, Wiberg J, Svanborg E, Fridlund B. 6-month CPAP-treatment in a young male patient with severe obstructive sleep apnoea syndrome — a case study from the couple's perspective. *European Journal of Cardiovascular Nursing*. 2008;7(2):103-112. doi:10.1016/j.ejcnurse.2006.11.004
102. Broström A, Nilsen P, Johansson P, et al. Putative facilitators and barriers for adherence to CPAP treatment in patients with obstructive sleep apnea syndrome: a qualitative content analysis. *Sleep Medicine*. 2010;11(2):126-130. doi:10.1016/j.sleep.2009.04.010
103. Dickerson SS, Akhu-Zaheya L. Life changes in individuals diagnosed with sleep apnea while accommodating to continuous positive airway pressure (CPAP) devices. *Rehabilitation Nursing*. 2007;32(6):241-250. doi:10.1002/j.2048-7940.2007.tb00181.x
104. Dickerson SS, Kennedy MC. CPAP devices: encouraging patients with sleep apnea. *Rehabilitation Nursing*. 2006;31(3):114-122. doi:10.1002/j.2048-7940.2006.tb00015.x
105. Gibson R, Campbell A, Mather S, Neill A. From diagnosis to long-term management: the experiences of older New Zealanders with obstructive sleep apnoea. *J Prim Health Care*. 2018;10(2):140-149. doi:10.1071/HC17072
106. Henry D, Rosenthal L. "Listening for his breath:" The significance of gender and partner reporting on the diagnosis, management, and treatment of obstructive sleep apnea. *Social Science & Medicine*. 2013;79:48-56. doi:10.1016/j.socscimed.2012.05.021

107. Hu S-T, Yu C-C, Lee P-S, Tsao L-I. Life experiences among obstructive sleep apnoea patients receiving continuous positive airway pressure therapy. *Journal of Clinical Nursing*. 2014;23(1-2):268-278. doi:10.1111/jocn.12414
108. Khan Nazia Naz S., Olomu Adesuwa B., Bottu Shireesha, Roller Margaret R., Smith Robert C. Semistructured motivational interviews of patients and caregivers to improve CPAP adherence: a qualitative analysis. *Journal of Clinical Sleep Medicine*. 2019;15(12):1721-1730. doi:10.5664/jcsm.8070
109. Luyster FS, Dunbar-Jacob J, Aloia MS, Martire LM, Buysse DJ, Strollo PJ. Patient and partner experiences with obstructive sleep apnea and CPAP treatment: a qualitative analysis. *Behavioral Sleep Medicine*. 2016;14(1):67-84. doi:10.1080/15402002.2014.946597
110. Møkleby M, Mengshoel AM. Devoted or negotiated routes of adherence: narratives of patients with obstructive sleep apnoea using a continuous positive airway pressure device. *Nursing Open*. 2019;6(3):1237-1244. doi:10.1002/nop2.325
111. Moreira T. Continuous positive airway pressure machines and the work of coordinating technologies at home. *Chronic Illness*. 2008;4(2):102-109. doi:10.1177/1742395308092481
112. Rodgers B. Breaking through limbo: experiences of adults living with obstructive sleep apnea. *Behavioral Sleep Medicine*. 2014;12(3):183-197. doi:10.1080/15402002.2013.778203
113. Shoukry G, Wong K, Bartlett D, Saini B. Treatment experience of people with obstructive sleep apnoea seeking continuous positive airways pressure device provision through community pharmacies – a role for pharmacists? *International Journal of Pharmacy Practice*. 2011;19(5):318-327. doi:10.1111/j.2042-7174.2011.00120.x
114. van de Mortel TF, Laird P, Jarrett C. Client perceptions of the polysomnography experience and compliance with therapy. *Contemporary Nurse*. 2000;9(2):161-168. doi:10.5172/conu.2000.9.2.161
115. Ward K, Gott M, Hoare K. Becoming a team: findings from a grounded theory study about living with CPAP. *Collegian*. 2018;25(1):81-88. doi:10.1016/j.colegn.2017.01.002
116. Ward K, Gott M, Hoare K. Mastering treatment for sleep apnoea: the grounded theory of bargaining and balancing life with Continuous Positive Airway Pressure (CPAP), in the context of decisional conflict and change theories. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*. 2019;20(3). doi:10.17169/fqs-20.3.3137
117. Willman M, Igelström H, Martin C, Åsenlöf P. Experiences with CPAP treatment in patients with obstructive sleep apnea syndrome and obesity. *Advances in Physiotherapy*. 2012;14(4):166-174. doi:10.3109/14038196.2012.704944
118. Ye L, Antonelli MT, Willis DG, Kayser K, Malhotra A, Patel SR. Couples' Experiences with CPAP Treatment: A Dyadic Perspective. *Sleep Health*. 2017;3(5):362-367. doi:10.1016/j.sleh.2017.07.003
119. National Health Service. Sleep apnoea - NHS. <https://www.nhs.uk/conditions/sleep-apnoea/>. Published 2019. Accessed March 5, 2020.

List of Figures and Figure Titles

Figure 1

PRISMA Flow Diagram ⁵⁹

List of Tables in Order of Reference in the Paper

Table 1

Full Search Strategy for MEDLINE Database and Database Specific Alternatives

Database: MEDLINE			Search fields
<i>Population</i>	Free text keywords	sleep apnoea OR sleep apnea OR OSA OR hypopnoea OR hypopnea	Title <i>OR</i> abstract
	MeSH terms	“Sleep Apnea, Obstructive”	N/A
<i>OR</i>			
<i>AND</i>			
<i>Exposure</i>	Free text keywords	positive airway pressure OR CPAP OR BiPAP OR (obstructive sleep apnoea OR OSA) N4 (treatment) OR (obstructive sleep apnea OR OSA) N4 (treatment)	Title <i>OR</i> abstract
	MeSH terms	“Continuous positive airway pressure”	N/A
<i>OR</i>			
<i>AND</i>			
<i>Outcome</i>	Free text keywords	experience* OR preference* OR report OR perspective* OR perception* OR influenc* OR barrier* OR facilitator* OR acceptance OR choice* OR attitude* OR adapt* OR cop* OR point of view* OR opinion* OR qualitative OR narrative* OR grounded theory OR focus group OR theme* OR thematic	Title <i>OR</i> abstract
	MeSH terms	“Treatment Adherence and Compliance+”	N/A
<i>Limits applied</i>	Journal article, English language and Human		
Database specific alternatives to above search strategy			
Database	Thesaurus terms used	Limits applied	
PsycINFO	<i>P</i> : “Sleep Apnea”	Academic journals	
	<i>E</i> : None	English language	
	<i>O</i> : “Client Attitudes”	Human	
CINAHL	<i>P</i> : “Sleep Apnea, Obstructive”	Journal article	
	<i>E</i> : “Continuous Positive Airway Pressure”	English language	
	<i>O</i> : “Patient Satisfaction+” OR “Patient Compliance+”	Human	
EMBASE	<i>P</i> : “exp sleep disordered breathing”	Article	
	<i>E</i> : “exp positive and expiratory pressure”	English language	
	<i>O</i> : “exp patient attitude” OR “exp patient compliance”	Human	

* denotes a truncation

+ indicates where a term was exploded

Table 2*Details of Papers Included in The Metasynthesis, Listed in Alphabetical Order*

Assigned letter First author Year Location	Data provided on participants with first-hand experience of PAP					Method of data collection	Method of qualitative analysis	Primary research question(s)
	N	Sex	Average age ^a (range)	Average AHI ^b	Average BMI ^c			
A Almeida ⁹⁸ 2013 Canada	22	13 male	60 (Not stated)	17.8 - 29.1	Not stated	Focus groups	Thematic analysis	What are the experiences of CPAP and oral appliance users? What are the factors that influence a patient's choice of treatment?
B Ayow ⁹⁹ 2009 Canada	8	4 male	43.3-48.8 (Not stated)	43 – 45.2	Not stated	Semi- structured interviews	Thematic analysis	What are the perceived factors that facilitate CPAP use? What are the perceived factors that prevent CPAP use and lead to abandonment of treatment?
C Bakker ¹⁰⁰ 2014 New Zealand	18	11 male	47 (30-71)	59.1 - 93	Not stated	Focus groups	Thematic analysis	What are Maori, Pacific and New Zealand European patients' experiences with CPAP treatment?
D Broström ¹⁰¹ 2008 Sweden	1	1 male	33	92	40	Semi- structured interview	Phenomenographic	What are the experiences of CPAP treatment of a young male with severe OSA from the couple's perspective?
E Broström ¹⁰² 2010 Sweden	23	13 male	59-62 (33-74)	40-44	34-35	Semi- structured interviews	Content analysis	What are the in-depth experiences associated with adherence to CPAP treatment in patients with OSA?

F Dickerson ¹⁰³ 2007 USA	20	9 male	52.8 (31-72)	Not stated	Not stated	Semi- structured interviews	Heideggerian hermeneutics	What are the experiences of individuals with sleep apnoea who use CPAP devices from diagnosis to 3 months? What is the usefulness and appropriateness of the Calgary sleep apnea quality of life (SAQOL) measurement tool?
G Dickerson ¹⁰⁴ 2006 USA	17	12 male	58.4 (40-73)	Not stated	Not stated	Semi- structured interviews	Heideggerian hermeneutics	What are the support group experiences of individuals with OSA who uses CPAP devices?
H Gibson ¹⁰⁵ 2018 New Zealand	16	15 male	71 (67-89)	Not stated	Not stated	Focus groups	Thematic analysis	What is the experience of diagnosis and management of OSA for older patients? What are the factors affecting acceptance of the current New Zealand services?
I Henry ¹⁰⁶ 2013 USA	12	7 male	49.3 (27-72)	57	Not stated	Semi- structured interviews	Content analysis	What is the significance of gender and partner-reporting in shaping the lay diagnosis, management, and treatment of OSA?
J Hu ¹⁰⁷ 2014 Taiwan	22	18 male	Not stated (37-68)	60.3	27.5	Semi- structured interviews	Grounded theory	What are OSA patients' feelings and perceptions in dealing with CPAP therapy?
K Khan ¹⁰⁸ 2019 USA	28	12 male	58 (Not stated)	Not stated	35.5	Semi- structured motivational interviews	Thematic analysis	What are OSA patients' preferences, partner experiences, barriers and facilitators to PAP adherence? What is the understanding of the educational content delivered and satisfaction with the multidimensional structured intervention?
L Luyster ¹⁰⁹	15	9 male	56 (Not stated)	Not stated	Not stated	Focus groups	Content analysis	What are both patients' and partners'

2016 USA								experiences of CPAP and the facilitators and barriers to CPAP use? What are suggestions for a new CPAP user program?
M Møkleby ¹¹⁰ 2019 Norway	7	5 male	Not stated (36-76)	Not stated	Not stated	Semi- structured interviews	Narrative analysis	How do patients with obstructive sleep apnoea experience and manage their use of CPAP?
N Moreira 2006 UK	2	Not known	Not known	Not known	Not known	Online discussion group	Analytic induction	What is the relationship between sleep and health from a sociological perspective?
O Moreira ¹¹¹ 2008 UK	Not known	Not known	Not known	Not known	Not known	Online discussion group	Analytic induction	How do users establish and maintain workable relationships between CPAP and other technological elements of the domestic environment?
P Rodgers ¹¹² 2014 USA	82	53 male	52 (21-82)	Not stated	Not stated	Interviews	Grounded theory	What are the experiences of individuals living with obstructive sleep apnoea?
Q Shoukry ¹¹³ 2011 Australia	20	15 male	57.5 (20-75)	Not stated	Not stated	Semi- structured interviews	Thematic analysis	What are the experiences of people with OSA, who have sourced their CPAP supply through a pharmacy?
R van de Mortel ¹¹⁴ 2000 Australia	19	15 male	54.8-65.9 (41-75)	Not stated	Not stated	Semi- structured interviews	Grounded theory	How do clients' experiences of sleep studies affect their compliance with therapy?

S1 Ward ⁷⁷ 2017 New Zealand	12	Not stated	Not stated	Not stated	Not stated	Semi- structured interviews	Grounded theory	What are experiences of living with continuous positive airway pressure?
S2 Ward ¹¹⁵ 2018 New Zealand	12	Not stated	Not stated	Not stated	Not stated	Semi- structured interviews	Grounded theory	What is it like to live with CPAP for sleep apnoea?
S3 Ward ¹¹⁶ 2019 New Zealand	12	Not stated	Not stated	Not stated	Not stated	Semi- structured interviews	Grounded theory	What are experiences of living with CPAP?
T Willman ¹¹⁷ 2012 Sweden	15	8 male	56.8 (41-71)	Not stated	38.5	Semi- structured interviews	Content analysis	What are personal experiences with CPAP in individuals with moderate or severe OSAS and obesity?
U Ye ¹¹⁸ 2017 USA	20	14 male	49.6 (not stated)	24.1	Not stated	Semi- structured interviews	Content analysis	What are couples' experiences with CPAP treatment? What are the facilitators and barriers to incorporating CPAP use into daily life?
V1 Zarhin ⁹² 2017 Israel	19	11 male	55.5-60.5 (not stated)	Not stated	Not stated	Semi- structured interviews	Grounded theory	What are patients' experiences of CPAP use and nonuse?
V2 Zarhin ⁸² 2018	19	11 male	55.5-60.5 (not stated)	Not stated	Not stated	Semi- structured interviews	Grounded theory	What happens to agency in the context of sleep? How is agency exchanged from body to technology in sleep?

