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Patient-centered care in obstructive sleep apnea: A vision for the future

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SUMMARY

Obstructive sleep apnea is a common condition, with multiple potential neurocognitive, cardiovascular, and metabolic consequences. Efficacious treatment is available, but patient engagement is typically required for treatment to be effective. Patients with sleep apnea are phenotypically diverse and have individual needs, preferences, and values that impact treatment decisions. There has been a shift in obstructive sleep apnea management from diagnosis to chronic care management. Making treatment decisions that incorporate an individual patient's values and preferences and are personalized for that patient's biology has the potential to improve patient outcomes. A patient-centered care approach in obstructive sleep apnea is reviewed including 1) determining patient-specific needs to guide treatment decisions, 2) understanding patient values, preferences, and other factors impacting treatment decisions and using shared decision-making, 3) enhancing patient education and support to improve treatment adherence, 4) promoting patient engagement, 5) optimizing care coordination, continuity of care, and access to care, and 6) determining and assessing patient-centered outcomes.

Keywords

Obstructive sleep apnea; Patient-centered care; Personalized medicine

Clinical vignettes

It is 1989. The patient is referred to the sleep laboratory by his primary physician for possible sleep apnea. On diagnostic in-laboratory polysomnography (PSG) four weeks later, the patient is found to have severe obstructive sleep apnea (OSA). The sleep specialist who interprets the study recommends that the patient be referred back for therapeutic PSG. The primary physician receives the report a few weeks later and places a referral for the recommended testing. Six weeks later, the patient returns to the sleep laboratory for therapeutic PSG and the sleep specialist recommends an effective positive airway pressure (PAP) setting. At the patient's follow-up visit with his primary physician, PAP is ordered.

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Conflicts of interest

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After several more weeks, the patient receives the equipment from a durable medical equipment company (DME). Shortly after starting PAP, the mask leaves red marks on the patient's face and the air is so dry he can barely use the therapy. He calls the DME who does not have orders to make any changes. The patient feels his sleep is worse, doesn't understand why he needs this anyway, and abandons therapy.

It is 2016. The patient, Mrs. Jones, is referred to the sleep center by her primary physician for possible sleep apnea. She is an accountant with hypertension and obesity who reports sleepiness affecting her work. She meets with a sleep specialist for a consultation and, based on her symptoms and comorbidities, the leading diagnosis is OSA. The pathophysiology and potential clinical consequences of OSA are discussed, possible treatment options are reviewed, and goals of treatment are explored. The patient indicates that she wants "not to be exhausted any more and is willing to do anything". Her only reluctance about PAP is whether PAP noise might affect her husband's sleep. Her concerns are addressed and she is provided with educational resources. Sleep testing is recommended, options for sleep testing are reviewed, and Mrs. Jones agrees to undergo home sleep apnea testing (HSAT).

HSAT is performed the following week and shows severe OSA. She is contacted with results and pros and cons of various treatments are discussed. She would like to lose weight in the long term, but after her initial visit with the sleep specialist and reviewing educational materials, she is most interested in PAP now. She is fit with an interface and started on auto-titrating PAP with heated humidification. She is also referred to a weight management program.

At her follow-up visit with a PAP specialist two weeks later in the center's PAP management program, she reports that she has been monitoring her own progress with a mobile app and is starting to feel more refreshed. However, she has some red marks from the mask in the morning and her mouth is dry. Her mask is refit, she is advised to replace the mask cushion regularly, she is reminded about the humidity adjustment, and asked to contact the sleep center to report on her progress. A week later, she sends a message via secure portal in the electronic medical record that she is doing better and thanks the team for their help. She also signs up for a sleep apnea patient-powered research network to share her data and connect with other patients through forums.

When Mrs. Jones returns to see her sleep specialist three months later, she "has amazing energy", her blood pressure is improved, and she has lost 10 pounds already. Her husband's sleep has also improved and he no longer needs to use earplugs to sleep. Data downloaded from her PAP device confirm excellent adherence and efficacy. She is congratulated on her success and ongoing follow-up is planned.

Conceptual framework

A paradigm shift is defined as "a time when the usual and accepted way of doing or thinking about something changes completely" [1]. Such a shift has occurred in the evaluation and management of patients with obstructive sleep apnea (OSA). In the 1980s, sleep laboratories mostly focused on the diagnosis of sleep disorders but rarely provided ongoing patient care.

Options for treatment of OSA were few and surgery or PAP was typically recommended, often with little patient education or follow-up. There were early calls for “commitment beyond diagnosis” [2], but these were largely unheeded. Healthcare in general at this time was disease-centric rather than patient-centric with doctors making treatment decisions about medical conditions with little input from patients.

Definition of patient-centered care

In 1986, the Picker Foundation took on a moral obligation to change healthcare, conducting research on the patient experience from the patient’s perspective and developing eight core principles of patient-centered care [3,4]. These principles included 1) respect for patients’ values, preferences, and expressed needs, 2) coordinated and integrated care, 3) information, communication, and education, 4) physical comfort, 5) emotional support, 6) involvement of family and friends, 7) continuity, and 8) access to care. In 2001, the Institute of Medicine published a landmark report calling for the redesign of the U.S. healthcare system involving all stakeholders, including health professionals, policy makers, purchasers of care, healthcare organizations, and patients [5]. Patient-centered care was included as one of six specific aims for quality health-care. In this report, patient-centered care was described as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions”. Since then, patient-centered care has become the gold standard in the U.S. and Europe, while specific attributes constituting patient-centeredness, as well as implementation and assessment methods, continue to evolve [6–9].

Definition of personalized care

It has become increasingly apparent that, given a set of risk factors, not all individuals will develop disease or that, given a disease, not all individuals will respond to the same therapy. Personalizing the right care for the right patient at the right time should therefore improve health outcomes. The National Human Genome Research Institute initially defined personalized care as “using an individual’s genetic profile to guide decisions made in regard to prevention, diagnosis, and treatment of disease”. This concept has been broadened to include, not only specific genes, but also modifications in gene expression independent of DNA sequence (epigenetics), gene expression profiles (transcriptomics), protein products (proteomics), and metabolites (metabolomics) [10]. Personalized medicine has also been called stratified medicine or precision medicine, and is incorporated into the concept of predictive, preventive, personalized, and participatory (P4) medicine [10,11]. P4 is a systems approach to medicine that includes predictive, preventive, personalized, and participatory aspects. P4 medicine extends genomic medicine by also including environmental and phenotypic measurements to better diagnose and treat disease and maximize wellness [12].

Why patient-centered care in OSA

OSA is a common condition, with an estimated prevalence of moderate-severe OSA in 17% and 9% of 50–70 year-old men and women, respectively [13]. OSA is associated with adverse health outcomes including excessive sleepiness [14], impaired cognition and performance [15], increased risk of motor vehicle accidents [16], mood disturbances [17], reduced quality of life [18], hypertension [19,20], cardiovascular disease [21–23], stroke

[23,24], diabetes [25], cancer [26], and increased mortality [27]. However, these associations are not universal and treatment may not necessarily affect outcomes. Treatment of OSA with PAP was not associated with improved neurocognitive outcomes in mild OSA in the apnea positive pressure long-term efficacy study (APPLES) [28] or with improved cardiovascular outcomes in moderate-severe OSA in the sleep apnea cardiovascular endpoints (SAVE) trial [29]. Such results challenge assumptions and serve as a reminder that a “one size fits all” approach may not be appropriate in OSA and that decisions regarding evaluation and management need to be individualized. Particularly in situations of clinical equipoise, it has been argued that patient-centered care is the right approach simply based on ethical grounds. When there is no clearly superior treatment based on current science, the principle of autonomy dictates that patients have a right to participate in decision-making [4].

Secondly, in a systematic review of patient-centered care, a patient-centered approach was found to be associated with improvement in outcomes, particularly in the areas of patient satisfaction and self-management [30]. Since humans spend one-third of their lives sleeping, it follows that self-management is critical to the success of any sleep therapy that requires active patient involvement.

Third, patient participation is essential for acquiring the big data necessary for the success of P4 medicine in a chronic disease such as OSA [31,32]. In clinical sleep medicine, the focus has shifted from OSA diagnosis to OSA chronic disease management, with the emergence of new models of care [33–35].

Finally, redesigning healthcare systems to provide excellent, efficient, and patient-centered care in chronic disease has the potential to, not only improve the triple aim of population health, patient experience, and cost, but also to increase satisfaction on the part of the entire healthcare team. A better healthcare model for patients with OSA would be expected to result in more “joy in the practice of sleep medicine” [36,37].

Applying a patient-centered care approach in OSA (see Table 1)

Determining patient-specific needs to guide OSA treatment decisions

OSA is a heterogeneous disorder. Potentially heritable risk factors include body weight and fat distribution, craniofacial morphology, ventilatory control, and upper airway control [38]. However, not all patients with these risk factors develop OSA. Additionally, there is individual susceptibility to OSA consequences. Not all patients with OSA will be sleepy [28] and not all patients with OSA will develop cardiovascular disease [23]. A systematic review and meta-analysis suggested potential differential effects of OSA depending on the cardiovascular outcome studied, severity of OSA, and gender [23]. Treatment decisions including whether (or not) to treat and best treatment choice depend on knowing who is at risk. Predicting treatment response based on available clinical information (such as positional variability, oral appliance titration, and drug induced sleep endoscopy), is imperfect [39]. OSA genetics are complex [32] and clinically useful biomarkers are not yet available [40]. There has been increased interest in understanding the different phenotypes of OSA to predict outcomes and personalize treatment decisions [32]. Physiologic, polysomnographic, and clinical phenotypes have been described as noted below.

Obesity is a major risk factor for OSA, weight loss improves OSA severity, obesity and OSA are associated with similar cardiovascular outcomes [41], and obesity and OSA are each associated with sleepiness [42]. However, the relationship between obesity and OSA is not straightforward. There are differential effects of PAP and weight loss on vascular inflammatory markers and cardiovascular disorders [41] and sleepiness does not resolve in all obese patients after treatment of OSA [42]. In addition to obesity and other causes of an anatomically compromised or collapsible upper airway, other potential pathophysiologic causes of OSA include a low arousal threshold to airway narrowing, an oversensitive ventilatory control system (high loop gain), and inadequate responsiveness of upper airway dilator muscles during sleep. When these physiologic parameters were assessed in a study of 75 patients with OSA, different physiologic phenotypes emerged [43]. While airway collapsibility was clearly important, 19% of patients had a relatively non-collapsible upper airway, and, in these patients, loop gain was much higher suggesting that an oversensitive ventilatory control mechanism was the driver for OSA. A model combining these four anatomic and nonanatomic traits has been developed and tested in 57 patients with OSA [44]. The model had good sensitivity (80%) and specificity (100%) for predicting OSA and may be useful to predict treatment response to specific therapies [45]. This same group recently tested combination therapy (hypnotic therapy and oxygen targeting loop gain and arousal threshold respectively) in a small single-blind randomized crossover study and achieved a significant response in 9/20 patients [46]. While this therapy needs further study before it can be widely recommended, these data suggest that understanding the underlying pathophysiology of OSA in a particular patient may improve treatment efficacy in that individual.

Other OSA phenotypes have been explored using cluster analysis. In a study of 1184 patients with mild-to-moderate OSA, six discrete groups were identified which varied in polysomnographic phenotype (sleep-stage and body-position predominance of OSA) as well as patient characteristics (age, gender, body mass index) [47]. REM-related OSA is more common in younger individuals and women, but effects on health outcomes and implications for treatment are uncertain and specific treatment options are lacking [48]. Positional sleep apnea is common, especially in those with milder OSA, and this finding has important treatment implications. Interestingly, in a study of 40 patients, positional therapy was successful in 68% of patients and short-term compliance with positional therapy strategies was excellent, but long-term compliance was poor with 65% no longer using these strategies at 13 mo [49].

In a study of 822 patients with moderate-severe OSA, three clinical phenotypes emerged based on symptom and comorbidity variables, including a “disturbed sleep group”, a “minimally symptomatic group”, and an “excessive daytime sleepiness group” [50]. Of these clinical symptoms, sleepiness has been the most studied. Sleepiness is part of the definition of OSA syndrome [33], may be less common in older adults [51], likely contributes to adverse outcomes (including motor vehicle accidents [16] and the development of hypertension [52] and cardiovascular disease [53]), affects treatment decisions [33], and modestly impacts PAP treatment adherence [54]. Insomnia is not as well studied as sleepiness but in a cohort of 702 patients with OSA, middle of the night insomnia improved significantly with PAP while initial and late insomnia tended to persist. Patients with initial

and late insomnia were less likely to adhere to PAP, raising the possibility that targeted treatment for insomnia could benefit PAP adherence [55].

Understanding patient values, preferences, and other factors impacting OSA treatment decisions: an opportunity for shared decision-making

Patient factors influence initial treatment choices as well as ongoing adherence to the chosen therapy. A highly efficacious treatment cannot be effective if not used. Understanding patient preferences and values is the first step in shared decision-making [4]. In a qualitative study of focus group sessions with 22 users of PAP or oral appliance therapy (OA) for treatment of OSA [56], patient-cited expectations of OSA treatment were, in order of most to least frequently mentioned: improved health, apnea elimination, improved sleep, reduced fatigue, reduced snoring, and bed-partner benefits. The patient factors impacting treatment choice were (most to least frequently mentioned): device effectiveness, transportability, embarrassment, and cost. Patient preference is increasingly being incorporated into study outcomes. In a study of OA for short-term use in 19 patients already using PAP with good adherence [57], 56% of patients preferred OA, 31% preferred PAP, and 13% had no preference (not significantly different). Interestingly, bed-partners expressed a preference for OA. In terms of perceived treatment effectiveness, 19% felt OA was more effective, 37% felt PAP was more effective, and 44% felt both treatments were equally effective (not statistically different). In the updated 2015 American Academy of Sleep Medicine (AASM) and American Academy of Dental Sleep Medicine clinical practice guideline, patient preference was cited as an indication for OA in patients with OSA, even in those patients with more severe OSA [58].

Psychological factors such as how individuals cope in new and difficult situations can predict treatment adherence. In a study of 23 PAP-naïve patients, a measure of active coping strategies was positively associated with objective PAP adherence, even after adjusting for respiratory disturbance index, sleepiness, and passive ways of coping [59]. A biopsychosocial model of PAP adherence, which incorporates physiologic, psychological, and social factors, may be a better way to conceptualize PAP adherence compared to models assessing only individual or a few factors [60].

Patients have beliefs and expectations about OSA and treatment even before they institute therapy. The health belief model proposes that a patient's readiness to act depends upon perceived severity of illness, perceived consequences if left untreated, perceived benefits of treatment, and perceived barriers to treatment. In a study of 77 patients newly diagnosed with OSA and naïve to PAP, health belief constructs explained 21.8% of the variance in PAP adherence [61]. A systematic literature review found that patients' beliefs influenced their experience of PAP, but that experiences were often defined from a healthcare perspective rather than a patient perspective [62]. The self-efficacy measure for sleep apnea questionnaire (SEMSA), a 26-item questionnaire with three sub-scales (perceived risks of OSA, outcome expectancies of treatment, and treatment self-efficacy), has been shown to predict clinical improvement with PAP use [63,64]. Additionally, motivational enhancement (i.e., a collaborative, rather than educational, interaction to maximize behavior change) has been shown to improve PAP adherence. In a randomized controlled trial of PAP plus

motivational enhancement versus PAP alone in 83 patients with moderate-severe OSA and without marked sleepiness, patients in the intervention group were asked, at regular brief sessions, their readiness to use PAP, their understanding of health risks associated with OSA, and the extent to which PAP could affect these risks and were encouraged to set personal goals for PAP use and personal rewards if goals achieved. Average nightly adherence at 6 mo was 97 min/night higher in the intervention group compared with the control group [65].

Health literacy, the ability to understand medical information related to healthcare, disease prevention, and health promotion, is required for patients to make truly informed choices and be active partners in their health. In a recent population cohort study, inadequate functional health literacy was independently associated with undiagnosed OSA with an odds ratio of 2.43 [66]. More research is needed to determine the relationship between health literacy and outcomes in OSA (such as treatment adherence) [67]. One way to potentially enhance initial understanding and shared decision-making is through patient decision aids (i.e., tools that present treatment options and help patients clarify their values). A prototype web-based patient decision aid for adults with obstructive sleep apnea has been developed; 96% of 80 patients who completed it found it useful in making a decision [68].

Enhancing patient education and support to improve OSA treatment adherence

PAP is considered the most efficacious therapy for OSA, yet some patients will not accept therapy while others will not adhere long-term. An early study of PAP adherence using covert compliance monitoring in 35 patients found that only 46% of patients who were prescribed PAP were compliant as defined by usage at least 4 h/night for at least 70% of nights [69]. Since then, many studies have been performed to determine predictors of and identify interventions to improve adherence [54,70].

A 2014 Cochrane systematic review of educational, supportive, and behavioral interventions in PAP-naïve patients with moderate-severe OSA found improved adherence with all three types of interventions (although often multiple elements were incorporated) [70]. Educational interventions were associated with increased PAP usage by 0.60 h/night (N = 508, seven studies; moderate-quality evidence) and increased adherence (defined as more than 4 h/night) from 57% to 70%. Ongoing supportive interventions were associated with increased PAP usage by 0.82 h/night (N = 803, 13 studies; low-quality evidence) and increased adherence from 59% to 75%. Behavioral therapy was associated with increased PAP usage of 1.44 h/night (N = 584, six studies; low-quality evidence) and increased adherence from 28% to 47%. A subsequent systematic review found little impact of stand-alone education programs, although patient education was typically incorporated into other programs that were effective including technological support programs, cognitive behavioral therapy, and multidimensional support programs [54]. In a cohort study of 403 patients, sleep specialist consultation prior to PSG was associated with increased PAP adherence by 58 min per night in the absence of any other interventions, presumably based on patient education, but not specifically tested [71]. In a prospective, multicenter study, accreditation-certification status of sleep centers and physicians was associated with better PAP adherence and better patient education as assessed by patient questionnaire [72]. Commonsense

recommendations to maximize PAP adherence, incorporating these strategies, have been published [73].

Social factors such as family/caregiver or spouse/partner support are associated with improved PAP adherence [54]. It has been suggested that broadening the focus of PAP adherence interventions from individual patients to a dyadic unit (patient and spouse/partner) could improve PAP use, but more research in this area is needed [74].

The use of trained peers (“peer buddies”) to provide patient support and promote treatment adherence has been studied in a prospective, randomized pilot study of 39 newly diagnosed patients [75]. PAP adherence was higher at one week in the peer buddy group compared to the usual care group by 1.2 h/night, and greater PAP adherence was still seen at the end of the 90-d trial period. Adherence defined as use at least 4 h/night was 63.6% in the peer-buddy group and 40% in the usual care group.

Promoting patient engagement in OSA treatment

Patients increasingly want to be engaged in their own health management, as evidenced by frequent patient access to online medical information, the explosion of mobile phone health apps and wearable technology, and increasing use of patient portals in electronic medical records. Both patient and physician attitudes towards technology in medicine are shifting [76]. According to a 2015 intercontinental marketing statistics (IMS) institute for healthcare informatics report [77], there are over 165,000 mobile health apps available to consumers. Most target wellness (e.g., fitness, lifestyle, exercise and diet), but approximately 25% focus on disease and treatment management. One in ten apps has the capability to connect to a device or sensor, thus improving the accuracy of data collection and potentially allowing a smartphone to be a diagnostic device. The use of sleep apps and wearable sleep-monitoring devices is common, but validation studies are often lacking [78]. In a study of 20 healthy volunteers who used a commercially available sleep app while undergoing PSG, the app was found to have high accuracy in sleep-wake detection (85.9%), but poor sleep stage discrimination (45.9%) [79].

Apps are in development to quantify snoring and sleep apnea, potentially allowing for more widespread screening and for better follow-up of patients after treatment. In a small study of 15 patients, using a microphone, accelerometer, and oximeter connected directly or wirelessly to a mobile phone, an app was able to correctly classify 100% of patients as having OSA and 87.5% as not having OSA [80]. In another study of 40 patients using snoring as detected by mobile phone placed on the chest with no external sensors compared with PSG, snoring time as measured by mobile phone was highly correlated with PSG ($r = 0.93$). The respiratory disturbance index as detected by dips in sound on the mobile phone was also highly correlated with that determined by PSG, with good sensitivity (0.70) and specificity (0.94) for diagnosing moderate OSA [81]. A novel contactless mobile app, which detects OSA by emitting frequency-modulated signals and listening for reflections, was found to perform well in a clinical study of 37 patients [82]. The app was able to correctly classify central apneas, obstructive apneas and hypopneas with correlation coefficients (r) of 0.996, 0.986 and 0.953 and was able to correctly classify severity of OSA (none, mild, moderate, severe) in 32 of 37 patients.

The ability of PAP devices to record data on usage, efficacy, leak, and other parameters has transformed the management of patients on PAP. Rather than simply asking patients how they are doing and periodically doing sleep studies for assessment, objective adherence, efficacy, and leak data can be assessed in real time and shared with patients. Objective PAP monitoring is now recommended routine practice [33,83]. Data can be downloaded directly from a media card on the PAP device or transferred to a cloud database via wired Ethernet cable, home Wi-Fi network, Bluetooth connection, or cellular connection, and then accessed remotely.

Cloud-based systems for storing PAP data have made it easier for the entire healthcare team to access data and provide support, as well as to potentially improve outcomes. In a study of 75 patients with moderate-severe OSA randomized to PAP treatment with web-based PAP monitoring and support versus standard PAP treatment, mean daily PAP adherence at 3 mo was 87 min higher in the monitored group [84]. Additionally, with newer PAP devices, patients are now able to access their own PAP data on any electronic device to see their progress in real-time and two studies suggest that patient access can improve initial adherence. In a randomized parallel group study of 241 patients with at least moderate OSA randomized to internet-access to PAP data versus usual care, adherence to PAP was higher at 2 mo in the intervention group (4.1 ± 2.3 and 3.4 ± 2.4 h/night, respectively). Participants randomized to the intervention group increased their use of the internet to obtain OSA information but not general health information. The majority of patients did not express concern over data being available on the internet. In another study of web-based patient access to PAP data including 138 patients with newly diagnosed at least mild OSA randomized to web-access, web-access plus financial incentive, or usual care [85], patients who had access to their own data had increased PAP adherence at one week (6.3 ± 2.5 h) compared with patients who did not (4.7 ± 3.3 h) and this difference was maintained over the 90 d of the study (5.0 ± 3.0 h versus 3.8 ± 3.3 h). Interestingly, adding a financial incentive did not increase adherence any further, suggesting that PAP use was primarily related to intrinsic motivation.

The ability to easily and objectively monitor PAP adherence is not without negative consequences. In the U.S. and internationally, some patients' insurance coverage for PAP is contingent upon meeting objective PAP compliance metrics, such as the Centers for Medicare and Medicaid Services (CMS) requirement of PAP usage at least 4 h/night at least 70% of nights [86]. Failure to meet this metric after a 90-d trial period results in loss of coverage for PAP in CMS beneficiaries. Loss of insurance coverage, in turn, results in patients not being treated at all rather than being partially treated. Additionally, those CMS beneficiaries who lose coverage for PAP but who would still like to pursue PAP therapy currently need to be restudied with PSG in order to re-qualify for PAP therapy. The CMS metric has not been rigorously studied and individual variability of response to PAP usage lower than the metric has been reported. In a study of 149 patients with severe OSA, thresholds of PAP usage above which further improvements were less likely were identified for Epworth sleepiness score (4 h), multiple sleep latency test (6 h), and functional outcomes of sleepiness questionnaire (7.5 h) [87]. However, a linear dose-response relationship was found between increased PAP usage and improvement in these parameters, and benefit was seen in some patients with PAP usage that would not have met the CMS compliance metric.

The proportion of patients who benefited from less than 2 h PAP usage was 41%, 33%, and 12.5% for the Epworth sleepiness score, multiple sleep latency test, and functional outcomes of sleepiness questionnaire, respectively. In a more recent study of 113 consecutive PAP attempters, sub-threshold PAP users showed a significant decrease in insomnia and nonsignificant, small effects for sleepiness and nocturia [86]. While having a clear and defined compliance metric could theoretically result in more patients using PAP consistently so as not to lose insurance coverage for PAP, possible negative outcomes could include more re-qualifying studies being done resulting in increased healthcare costs, patients deciding not to re-qualify for PAP thereby not being treated at all, and the assumption that only 4 h of PAP is necessary nightly, leading to less overall PAP usage. Further study in this area is needed.

In addition to engaging patients in their own care, patient engagement may also take the form of advocacy or research on outcomes that are important to patients. The American Sleep Apnea Association, founded in 1990, is a “patient-led, nonprofit organization dedicated to the promotion of sleep health through research, advocacy and education” [88]. Initiatives include A.W.A.K.E.™ (a network of local education and support groups), CPAP assistance program (to help patients who otherwise cannot afford PAP), and the annual Sleepember® campaign (which encourages the public to take healthy actions and helps raise funds to promote greater awareness and support research to improve patient outcomes). As described below, the patient-centered outcomes research institute (PCORI) was established in 2010 to develop and expand a health data network to improve the quality and relevance of evidence available to all stakeholders, including patients, to make informed health decisions [89]. Patients have an integral role in the entire process of patient-centered research including identifying research questions, study design and implementation, and dissemination. The use of online portals facilitates education and free exchange of ideas and serves as a dataset for analysis of patient-entered information.

Optimizing care coordination, continuity of care, and access to care in OSA

The 2009 AASM guideline for OSA recommended that OSA be approached as a chronic disease requiring long-term, multidisciplinary management [33]. In 2010, the AASM Future of Sleep Medicine task force was convened, and among other topics, healthcare delivery models were reviewed including the patient-centered medical home (PCMH) model of care, in which each patient has an ongoing relationship with a physician-led team [90]. The consensus was that sleep physicians are best described as partners or “neighbors” in the care process, working in close collaboration with the primary care physician. The sleep center thus serves as PCMH-neighbor providing patient-centered sleep services to the PCMH-hub. Coordinated management might take the form of informal exchange, formal consultation, or co-management. It was noted that effective communication and an integrated electronic health record were both essential for optimal care delivery. Since then, proposed strategies to improve the care of sleep disorders patients have included development of multidisciplinary specialty clinics, optimized use of information technology, and adoption of reliable performance measures [91].

Given the large burden of sleep disorders and the relatively few board-certified sleep physicians, timely access to care may be compromised. One solution is for patients with sleep disorders to receive care from a sleep care team including, not just sleep physicians, but also advanced practice professionals, clinical psychologists, sleep technologists, and other clinicians trained in sleep [34]. Currently, 40% of 271 AASM member centers surveyed report employing an advanced practice registered nurse or physician assistant, mostly in clinical roles [92]. Another approach is to use a collaborative care model interfacing sleep specialists with primary care providers. In a randomized, parallel group clinical trial, 137 patients with sleep disorder complaints were randomized to a onetime consultation with a sleep physician who provided diagnostic feedback and treatment recommendations to the patient and primary care physician or usual primary care [93]. The one-time sleep consultation was associated with more provider-initiated sleep-focused interventions (e.g., referral for testing) and improved patient-focused outcomes at 10 mo (e.g., sleep diary wake time and sleep efficiency). A third approach is to shift management of straightforward OSA to the primary care team but reserve management of more complicated sleep breathing disorders to the sleep specialist. In a randomized, controlled, non-inferiority study of 155 patients with straightforward moderate-severe OSA who were at least mildly sleepy, primary care management using trained nurses was noninferior to sleep specialist management [94]. There was no difference in the primary outcome of sleepiness at 6 mo and no differences in secondary outcomes of quality of life, OSA symptoms, PAP adherence, and patient satisfaction. More patients in the primary care group withdrew from the study compared with the sleep specialist group. Within-trial sleep-related costs were lower in the primary care group, but the study did not assess indirect costs or potential long-term costs. In a recent special article, the AASM Board of Directors outlined a five-point comprehensive plan to confront workforce challenges including “growing sleep fellowship programs, exploring novel sleep medicine training opportunities, creating and fostering the sleep team (with special emphasis on engagement of primary care providers), embracing the role of consumer sleep technologies, and expanding the reach of sleep specialists through telemedicine” [95].

Access to care for straightforward OSA may be improved by incorporating a home-based approach for testing and treatment rather than a sleep laboratory-based approach, and a home based approach may also be preferable to patients. The success of a completely ambulatory strategy was first demonstrated in a study of 68 patients with 90% clinical probability of OSA subsequently diagnosed by HSAT and then randomly assigned to PAP as determined by auto-titration or by laboratory PSG [96]. At 3 mo, there were no differences in objective treatment efficacy, sleepiness, or sleep apnea quality of life. PAP adherence was higher in the completely ambulatory arm. All patients were satisfied with their diagnosis and management, but given the opportunity, 62% of patients in the PSG group would have preferred home management while only 6% of the home management group would have preferred laboratory management.

Subsequent randomized studies comparing ambulatory and laboratory-based approaches have generally found an ambulatory approach noninferior to a laboratory approach in adults with OSA, especially in those with a high likelihood of moderate-severe disease, although indices of sleep disordered breathing are systematically underestimated with ambulatory

testing compared with laboratory-based testing [97–100]. In a randomized study of 131 veterans with suspected OSA (who were mostly male, overweight, sleepy, and ultimately found to have severe OSA based on reported mean apnea–hypopnea index (AHI)), functional outcomes and PAP adherence were noninferior in the ambulatory arm compared with the laboratory arm [97]. In the HomePAP study, a multi-site randomized trial of a larger, more diverse population but selected for a high probability of moderate-severe OSA, PAP acceptance, titration success, time to treatment, and Epworth sleepiness score were similar in the ambulatory and laboratory-based approaches, and PAP usage was better in the ambulatory arm [99]. The impact of HSAT versus in-laboratory PSG on therapeutic decision-making was investigated in a randomized multicenter study of 366 patients with intermediate-high suspicion of OSA [98]. For the entire group, overall therapeutic decision-making agreement between the two approaches was 76%, but was much better in the group with severe OSA (AHI at least 30/h (agreement level 91%) and lower in the group with AHI between 5/h and 30/h (agreement level 57%), suggesting that an ambulatory approach may perform better in more severe OSA. To assess ambulatory monitoring in a more real-world setting, this same group examined three nights of HSAT vs single PSG in 56 patients without high pretest probability or with comorbidities [100]. In this small study, for a PSG AHI of at least 5/h, an HSAT AHI of 5/h effectively excluded and confirmed OSA and for a PSG AHI of at least 15/h, an HSAT AHI of at least 22/h confirmed OSA and an HSAT AHI of less than 7/h excluded OSA. The utility of HSAT in very mild OSA in adults has not been well studied but, in a study of 100 children, the underestimation in AHI by HSAT was found to significantly affect management decisions, especially in those with AHI between 1/h and 10/h [101].

Telemedicine has the potential to improve access to care as well as patient engagement and outcomes. Sleep telemedicine has been the subject of two recent reviews [102,103] and an AASM position paper [104] and can be defined as the “use of sleep-related medical information exchanged from one site to another via electronic communications to improve a patient’s health.” Synchronous telemedicine refers to medical care delivered in real time, via internet, telephone, or clinical video telehealth encounter with the patient at an originating site (which could be a clinic or health center) and the sleep specialist at a distant site. This type of tele-medicine meets all the requirements of an in-person visit. A patient presenter may be present at the originating site to facilitate communication and peripheral devices such as electronic stethoscopes and intraoral cameras may be used. Asynchronous telemedicine refers to lack of real-time interaction through “store and forward” technologies. Examples include review of cloud-based PAP data, interpretation of home sleep studies, and electronic messaging. Synchronous telemedicine can improve access to sleep specialist care for patients in geographic areas remote from sleep centers and, even in urban areas, synchronous telemedicine may improve access by reducing travel time and other barriers such as parking and fuel costs. In a survey of 123 patients seen at an academic sleep clinic, 60% reported willingness to try synchronized telemedicine visits despite lack of prior experience [105]. In a prospective, parallel-group, randomized pilot study of 60 veterans, a telemedicine pathway including an initial clinical video telehealth visit, HSAT, wireless PAP monitoring, and telephone follow-up was compared to a traditional in-person care model [106]. At 3 mo, no differences were found in functional outcomes, patient satisfaction,

dropout rates, or PAP adherence. Feedback from patients on the telemedicine pathway was positive.

Determining and assessing patient-centered outcomes in OSA

For research to be patient-centered, outcomes that matter to patients need to be assessed. In a recent systematic review of patient-reported outcome measures (PROMs) in OSA [107], 22 PROMs were identified in the literature, but many did not involve patients in the development of the PROM and many were not fully validated. Four PROMs were found to have good content validity: the obstructive sleep apnea patient-oriented severity index (OSA-POSI) [108] the Mageri obstructive sleep apnea syndrome questionnaire (MOSAS) [109], the Quebec sleep questionnaire (QSQ) [110], and the sleep apnea quality of life index (SAQLI) [111].

As noted above, PCORI was established in 2010 with the goal of creating a network of patient-powered research networks (PPRNs) to foster patient-centered comparative effectiveness research [89]. The sleep apnea patient-centered outcomes network (SAPCON) is one of 29 PPRNs that were approved in 2013 and is currently a National patient-centered clinical research network (PCORnet)-affiliated PPRN. SAPCON includes patients, clinicians, researchers, and other stakeholders. The public face of SAPCON is MyApnea.org [112], an online portal freely available to all. Within the portal, patients can respond to surveys, look up information, engage in forums, read narratives, and propose and vote on research questions. SAPCON's goals include building a large and diverse online community and supporting a patient-centered approach to research. SAPCON is currently an active participant in a pan-network trial evaluating mindfulness and wellness. It is also funded by the American Sleep Medicine Foundation to conduct patient-centered evaluations of portal engagement.

The “sustainable methods, algorithms, and research tools for delivering optimal care study” (SMART DOCS) is a PCORI-sponsored randomized, two-arm, single center, long-term comparative effectiveness study designed to compare a patient-centered and coordinated-care management approach with a conventional care approach in patients with sleep disorder complaints [113]. Features of the patient-centered approach include standardized intake (the Alliance sleep questionnaire which integrates other existing scales and questionnaires), use of novel technology, co-management with primary care, integration of multidisciplinary sleep team members for education and support, and enhanced patient-provider data and information sharing through a dedicated, easy-to-understand web-portal. The hope is that such an approach will enable patients to make more informed healthcare decisions and allow providers to assist patients in achieving their preferred outcomes.

Abbreviations

AASM	American Academy of Sleep Medicine
AHI	apneahypopnea index
APPLES	apnea positive pressure long-term efficacy study

CMS	centers for Medicare and Medicaid services
DME	durable medical equipment company
HSAT	home sleep apnea testing
IMS	intercontinental marketing statistics
MOSAS	Maugeri obstructive sleep apnea questionnaire
OA	oral appliance
OSA	obstructive sleep apnea
OSA-POS	obstructive sleep apnea patient-oriented severity index
PAP	positive airway pressure
PCMH	patient-centered medical home
PCORI	patient-centered outcomes research institute
PPRN	patient-powered research network
PROM	patient-reported outcome measure
PSG	polysomnography
P4	predictive, preventive, personalized, participatory
QSQ	Quebec sleep questionnaire
SAPCON	sleep apnea patient-centered outcomes network
SAQLI	sleep apnea quality of life index
SAVE	sleep apnea cardiovascular endpoints
SMARTDOGS	sustainable methods, algorithms, and research tools for delivering optimal care study

References

* The most important references are denoted by an asterisk.

1. Cambridge Dictionary. [accessed 17.08.16] Paradigm shift. <http://dictionary.cambridge.org/us/dictionary/english/paradigm-shift%3E>
2. Norman SE, Cohn MA. Follow-up care at sleep disorders centers: a commitment beyond diagnosis. *Sleep*. 1985; 8(1):71–3. [PubMed: 2986270]
- *3. Gerteis, M., Edgman-Levitan, S., Daley, J., Delbanco, TL. *Through the patient's eyes*. San Francisco: Jossey-Bass; 1993.
4. Barry MJ, Edgman-Levitan S. Shared decision making—pinnacle of patient-centered care. *N Engl J Med*. 2012; 366(9):780–1. [PubMed: 22375967]
5. Institute of Medicine. *Crossing the quality chasm: a new health system for the 21st century*. Washington DC: 2001.

6. Epstein RM, Street RL Jr. The values and value of patient-centered care. *Ann Fam Med*. 2011; 9(2): 100–3. [PubMed: 21403134]
7. Scholl I, Zill JM, Harter M, Dirmaier J. An integrative model of patient-centeredness – a systematic review and concept analysis. *PLoS One*. 2014; 9(9):e107828. [PubMed: 25229640]
8. Davis K, Schoenbaum SC, Audet AM. A 2020 vision of patient-centered primary care. *J Gen Intern Med*. 2005; 20(10):953–7. [PubMed: 16191145]
9. Tanenbaum SJ. What is patient-centered care? A typology of models and missions. *Health Care Anal*. 2015; 23(3):272–87. [PubMed: 23807735]
10. Li A, Meyre D. Jumping on the train of personalized medicine: a primer for non-geneticist clinicians: part 3. Clinical applications in the personalized medicine area. *Curr Psychiatry Rev*. 2014; 10(2):118–32. [PubMed: 25598768]
11. Hood L, Friend SH. Predictive, personalized, preventive, participatory (P4) cancer medicine. *Nat Rev Clin Oncol*. 2011; 8(3):184–7. [PubMed: 21364692]
12. Sagner M, McNeil A, Puska P, Auffray C, Price ND, Hood L, et al. The P4 health spectrum – a predictive, preventive, personalized and participatory continuum for promoting healthspan. *Prog Cardiovasc Dis*. 2016. <http://dx.doi.org/10.1016/j.pcad.2016.08.002>
13. Peppard PE, Young T, Barnet JH, Palta M, Hagen EW, Hla KM. Increased prevalence of sleep-disordered breathing in adults. *Am J Epidemiol*. 2013; 177(9):1006–14. [PubMed: 23589584]
14. Gottlieb DJ, Whitney CW, Bonekat WH, Iber C, James GD, Lebowitz M, et al. Relation of sleepiness to respiratory disturbance index: the Sleep Heart Health Study. *Am J Respir Crit Care Med*. 1999; 159(2):502–7. [PubMed: 9927364]
15. Stranks EK, Crowe SF. The cognitive effects of obstructive sleep apnea: an updated meta-analysis. *Arch Clin Neuropsychol*. 2016; 31(2):186–93. [PubMed: 26743325]
16. 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):573–81. [PubMed: 20465027]
17. Peppard PE, Szklo-Coxe M, Hla KM, Young T. Longitudinal association of sleep-related breathing disorder and depression. *Arch Intern Med*. 2006; 166(16):1709–15. [PubMed: 16983048]
18. Baldwin CM, Griffith KA, Nieto FJ, O'Connor GT, Walsleben JA, Redline S. The association of sleep-disordered breathing and sleep symptoms with quality of life in the Sleep Heart Health Study. *Sleep*. 2001; 24(1):96–105. [PubMed: 11204058]
19. Peppard PE, Young T, Palta M, Skatrud J. Prospective study of the association between sleep-disordered breathing and hypertension. *N Engl J Med*. 2000; 342(19):1378–84. [PubMed: 10805822]
20. Nieto FJ, Young TB, Lind BK, Shahar E, Samet JM, Redline S, et al. Association of sleep-disordered breathing, sleep apnea, and hypertension in a large community-based study. *Sleep Heart Health Study JAMA*. 2000; 283(14):1829–36. [PubMed: 10770144]
21. Shahar E, Whitney CW, Redline S, Lee ET, Newman AB, Nieto FJ, et al. Sleep-disordered breathing and cardiovascular disease: cross-sectional results of the Sleep Heart Health Study. *Am J Respir Crit Care Med*. 2001; 163(1):19–25. [PubMed: 11208620]
22. Marin JM, Carrizo SJ, Vicente E, Agusti AG. Long-term cardiovascular outcomes in men with obstructive sleep apnoea-hypopnoea with or without treatment with continuous positive airway pressure: an observational study. *Lancet*. 2005; 365(9464):1046–53. [PubMed: 15781100]
23. Loke YK, Brown JW, Kwok CS, Niruban A, Myint PK. Association of obstructive sleep apnea with risk of serious cardiovascular events: a systematic review and meta-analysis. *Circ Cardiovasc Qual Outcomes*. 2012; 5(5):720–8. [PubMed: 22828826]
24. Yaggi HK, Concato J, Kernan WN, Lichtman JH, Brass LM, Mohsenin V. Obstructive sleep apnea as a risk factor for stroke and death. *N Engl J Med*. 2005; 353(19):2034–41. [PubMed: 16282178]
25. Botros N, Concato J, Mohsenin V, Selim B, Doctor K, Yaggi HK. Obstructive sleep apnea as a risk factor for type 2 diabetes. *Am J Med*. 2009; 122(12):1122–7. [PubMed: 19958890]
26. Nieto FJ, Peppard PE, Young T, Finn L, Hla KM, Farre R. Sleep-disordered breathing and cancer mortality: results from the Wisconsin Sleep Cohort Study. *Am J Respir Crit Care Med*. 2012; 186(2):190–4. [PubMed: 22610391]

27. Young T, Finn L, Peppard PE, Szklo-Coxe M, Austin D, Nieto FJ, et al. Sleep disordered breathing and mortality: eighteen-year follow-up of the Wisconsin sleep cohort. *Sleep*. 2008; 31(8):1071–8. [PubMed: 18714778]
28. Quan SF, Budhiraja R, Batool-Anwar S, Gottlieb DJ, Eichling P, Patel S, et al. Lack of impact of mild obstructive sleep apnea on sleepiness, Mood Quality of Life. *Southwest J Pulm Crit Care*. 2014; 9(1):44–56. [PubMed: 25232509]
29. McEvoy RD, Antic NA, Heeley E, Luo Y, Ou Q, Zhang X, et al. Coordinators, CPAP for prevention of cardiovascular events in obstructive sleep apnea. *N Engl J Med*. 2016; 375(10):919–31. [PubMed: 27571048]
30. Rathert C, Wyrwich MD, Boren SA. Patient-centered care and outcomes: a systematic review of the literature. *Med Care Res Rev*. 2013; 70(4):351–79. [PubMed: 23169897]
31. Hood L, Auffray C. Participatory medicine: a driving force for revolutionizing healthcare. *Genome Med*. 2013; 5(12):110. [PubMed: 24360023]
- *32. Pack AI. Application of personalized, predictive, preventative, and participatory (P4) medicine to obstructive sleep apnea. A roadmap for improving care? *Ann Am Thorac Soc*. 2016; 13(9):1456–67. [PubMed: 27387483]
33. Epstein LJ, Kristo D, Strollo PJ Jr, Friedman N, Malhotra A, Patil SP, et al. Clinical guideline for the evaluation, management and long-term care of obstructive sleep apnea in adults. *J Clin Sleep Med*. 2009; 5(3):263–76. [PubMed: 19960649]
34. Badr MS. The future is here. *J Clin Sleep Med*. 2013; 9(9):841–3. [PubMed: 23997694]
35. Heatley EM, Harris M, Battersby M, McEvoy RD, Chai-Coetzer CL, Antic NA. Obstructive sleep apnoea in adults: a common chronic condition in need of a comprehensive chronic condition management approach. *Sleep Med Rev*. 2013; 17(5):349–55. [PubMed: 23434125]
36. Morgenthaler TI. Joy in the practice of sleep medicine. *J Clin Sleep Med*. 2014; 10(8):829–32. [PubMed: 25126025]
37. Bodenheimer T, Sinsky C. From triple to quadruple aim: care of the patient requires care of the provider. *Ann Fam Med*. 2014; 12(6):573–6. [PubMed: 25384822]
38. Riha RL, Gislason T, Diefenbach K. The phenotype and genotype of adult obstructive sleep apnoea/hypopnoea syndrome. *Eur Respir J*. 2009; 33(3):646–55. [PubMed: 19251800]
39. Edwards BA, Landry S, Joosten SA, Hamilton GS. Personalized medicine for obstructive sleep apnea therapies: are we there yet? *Sleep Med Clin*. 2016; 11(3):299–311. [PubMed: 27542876]
40. Khalyfa A, Gileles-Hillel A, Gozal D. The challenges of precision medicine in obstructive sleep apnea. *Sleep Med Clin*. 2016; 11(2):213–26. [PubMed: 27236058]
41. Hudgel, DW. Critical review: CPAP and weight management of obstructive sleep apnea cardiovascular co-morbidities. *Sleep Med Rev*. 2016. <http://dx.doi.org/10.1016/j.smrv.2016.12.001>
42. Panossian LA, Veasey SC. Daytime sleepiness in obesity: mechanisms beyond obstructive sleep apnea – a review. *Sleep*. 2012; 35(5):605–15. [PubMed: 22547886]
- *43. Eckert DJ, White DP, Jordan AS, Malhotra A, Wellman A. Defining phenotypic causes of obstructive sleep apnea. Identification of novel therapeutic targets. *Am J Respir Crit Care Med*. 2013; 188(8):996–1004. [PubMed: 23721582]
44. Owens RL, Edwards BA, Eckert DJ, Jordan AS, Sands SA, Malhotra A, et al. An integrative model of physiological traits can be used to predict obstructive sleep apnea and response to non positive airway pressure therapy. *Sleep*. 2015; 38(6):961–70. [PubMed: 25515107]
45. Deacon NL, Jen R, Li Y, Malhotra A. Treatment of obstructive sleep apnea. Prospects for personalized combined modality therapy. *Ann Am Thorac Soc*. 2016; 13(1):101–8. [PubMed: 26569377]
46. Edwards BA, Sands SA, Owens RL, Eckert DJ, Landry S, White DP, et al. The combination of supplemental oxygen and a hypnotic markedly improves obstructive sleep apnea in patients with a mild to moderate upper airway collapsibility. *Sleep*. 2016; 39(11):1973–83. [PubMed: 27634790]
47. Joosten SA, Hamza K, Sands S, Turton A, Berger P, Hamilton G. Phenotypes of patients with mild to moderate obstructive sleep apnoea as confirmed by cluster analysis. *Respirology*. 2012; 17(1):99–107. [PubMed: 21848707]
48. Mokhlesi B, Punjabi NM. “REM-related” obstructive sleep apnea: an epiphenomenon or a clinically important entity? *Sleep*. 2012; 35(1):5–7. [PubMed: 22215911]

49. de Vries GE, Hoekema A, Doff MH, Kerstjens HA, Meijer PM, van der Hoeven JH, et al. Usage of positional therapy in adults with obstructive sleep apnea. *J Clin Sleep Med*. 2015; 11(2):131–7. [PubMed: 25406271]
50. Ye L, Pien GW, Ratcliffe SJ, Bjornsdottir E, Arnardottir ES, Pack AI, et al. The different clinical faces of obstructive sleep apnoea: a cluster analysis. *Eur Respir J*. 2014; 44(6):1600–7. [PubMed: 25186268]
51. Morrell MJ, Finn L, McMillan A, Peppard PE. The impact of ageing and sex on the association between sleepiness and sleep disordered breathing. *Eur Respir J*. 2012; 40(2):386–93. [PubMed: 22241742]
52. Kapur VK, Resnick HE, Gottlieb DJG. Sleep Heart Health Study. Sleep disordered breathing and hypertension: does self-reported sleepiness modify the association? *Sleep*. 2008; 31(8):1127–32. [PubMed: 18714785]
53. Empana JP, Dauvilliers Y, Dartigues JF, Ritchie K, Gariepy J, Jouven X, et al. Excessive daytime sleepiness is an independent risk indicator for cardiovascular mortality in community-dwelling elderly: the three city study. *Stroke*. 2009; 40(4):1219–24. [PubMed: 19246707]
- *54. Sawyer AM, Gooneratne NS, Marcus CL, Ofer D, Richards KC, Weaver TE. A systematic review of CPAP adherence across age groups: clinical and empiric insights for developing CPAP adherence interventions. *Sleep Med Rev*. 2011; 15(6):343–56. [PubMed: 21652236]
55. Bjornsdottir E, Janson C, Sigurdsson JF, Gehrman P, Perlis M, Juliusson S, et al. Symptoms of insomnia among patients with obstructive sleep apnea before and after two years of positive airway pressure treatment. *Sleep*. 2013; 36(12):1901–9. [PubMed: 24293765]
56. Almeida FR, Henrich N, Marra C, Lynd LD, Lowe AA, Tsuda H, 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):659–66. [PubMed: 22833346]
57. Almeida FR, Mulgrew A, Ayas N, Tsuda H, Lowe AA, Fox N, et al. Mandibular advancement splint as short-term alternative treatment in patients with obstructive sleep apnea already effectively treated with continuous positive airway pressure. *J Clin Sleep Med*. 2013; 9(4):319–24. [PubMed: 23585745]
58. Ramar K, Dort LC, Katz SG, Lettieri CJ, Harrod CG, Thomas SM, et al. Clinical practice guideline for the treatment of obstructive sleep apnea and snoring with oral appliance therapy: an update for 2015. *J Clin Sleep Med*. 2015; 11(7):773–827. [PubMed: 26094920]
59. Stepnowsky CJ Jr, Bardwell WA, Moore PJ, Ancoli-Israel S, Dimsdale JE. Psychologic correlates of compliance with continuous positive airway pressure. *Sleep*. 2002; 25(7):758–62. [PubMed: 12405612]
60. Crawford MR, Espie CA, Bartlett DJ, Grunstein RR. Integrating psychology and medicine in CPAP adherence – new concepts? *Sleep Med Rev*. 2014; 18(2):123–39. [PubMed: 23725820]
61. Olsen S, Smith S, Oei T, Douglas J. Health belief model predicts adherence to CPAP before experience with CPAP. *Eur Respir J*. 2008; 32(3):710–7. [PubMed: 18417510]
62. 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 Med Rev*. 2014; 18(4):357–66. [PubMed: 24581718]
63. Weaver TE, Maislin G, Dinges DF, Younger J, Cantor C, McCloskey S, et al. Self-efficacy in sleep apnea: instrument development and patient perceptions of obstructive sleep apnea risk, treatment benefit, and volition to use continuous positive airway pressure. *Sleep*. 2003; 26(6):727–32. [PubMed: 14572127]
64. Baron KG, Berg CA, Czajkowski LA, Smith TW, Gunn HE, Jones CR. Self-efficacy contributes to individual differences in subjective improvements using CPAP. *Sleep Breath*. 2011; 15(3):599–606. [PubMed: 20844971]
65. Bakker JP, Wang R, Weng J, Aloia MS, Toth C, Morrical MG, et al. Motivational enhancement for increasing adherence to CPAP: a randomized controlled trial. *Chest*. 2016; 150(2):337–45. [PubMed: 27018174]
66. Li JJ, Appleton SL, Wittert GA, Vakulin A, McEvoy RD, Antic NA, et al. The relationship between functional health literacy and obstructive sleep apnea and its related risk factors and comorbidities in a population cohort of men. *Sleep*. 2014; 37(3):571–8. [PubMed: 24587580]

67. Hackney JE, Weaver TE, Pack AI. Health literacy and sleep disorders: a review. *Sleep Med Rev.* 2008; 12(2):143–51. [PubMed: 18222098]
68. Trenaman L, Munro S, Almeida F, Ayas N, Hicklin J, Bansback N. Development of a patient decision aid prototype for adults with obstructive sleep apnea. *Sleep Breath.* 2016; 20(2):653–61. [PubMed: 26449553]
69. Kribbs NB, Pack AI, Kline LR, Smith PL, Schwartz AR, Schubert NM, et al. Objective measurement of patterns of nasal CPAP use by patients with obstructive sleep apnea. *Am Rev Respir Dis.* 1993; 147(4):887–95. [PubMed: 8466125]
70. Wozniak DR, Lasserson TJ, Smith I. Educational, supportive and behavioural interventions to improve usage of continuous positive airway pressure machines in adults with obstructive sleep apnoea. *Cochrane Database Syst Rev.* 2014; 1:CD007736.
71. Pamidi S, Knutson KL, Ghods F, Mokhlesi B. The impact of sleep consultation prior to a diagnostic polysomnogram on continuous positive airway pressure adherence. *Chest.* 2012; 141(1):51–7. [PubMed: 21700685]
72. Parthasarathy S, Subramanian S, Quan SF. A multicenter prospective comparative effectiveness study of the effect of physician certification and center accreditation on patient-centered outcomes in obstructive sleep apnea. *J Clin Sleep Med.* 2014; 10(3):243–9. [PubMed: 24634620]
- *73. Wickwire EM, Lettieri CJ, Cairns AA, Collop NA. Maximizing positive airway pressure adherence in adults: a common-sense approach. *Chest.* 2013; 144(2):680–93. [PubMed: 23918114]
74. Ye L, Malhotra A, Kayser K, Willis DG, Horowitz JA, Aloia MS, et al. Spousal involvement and CPAP adherence: a dyadic perspective. *Sleep Med Rev.* 2015; 19:67–74. [PubMed: 24906222]
- *75. Parthasarathy S, Wendel C, Haynes PL, Atwood C, Kuna S. A pilot study of CPAP adherence promotion by peer buddies with sleep apnea. *J Clin Sleep Med.* 2013; 9(6):543–50. [PubMed: 23772186]
76. Miller, G. [accessed 04.10.16] 2016. <http://www.medscape.com/features/slideshow/public/technology-in-medicine-page=1>
77. IMS Institute for Healthcare Informatics. Patient adoption of mHealth: use, evidence and remaining barriers to mainstream acceptance. 2015
78. Ko PR, Kientz JA, Choe EK, Kay M, Landis CA, Watson NF. Consumer sleep technologies: a review of the landscape. *J Clin Sleep Med.* 2015; 11(12):1455–61. [PubMed: 26156958]
79. Bhat S, Ferraris A, Gupta D, Mozafarian M, DeBari VA, Gushway-Henry N, et al. Is there a clinical role for smartphone sleep apps? Comparison of sleep cycle detection by a smartphone application to polysomnography. *J Clin Sleep Med.* 2015; 11(7):709–15. [PubMed: 25766719]
80. Al-Mardini M, Aloul F, Sagahyroon A, Al-Husseini L. Classifying obstructive sleep apnea using smartphones. *J Biomed Inf.* 2014; 52:251–9.
81. Nakano H, Hirayama K, Sadamitsu Y, Toshimitsu A, Fujita H, Shin S, et al. Monitoring sound to quantify snoring and sleep apnea severity using a smartphone: proof of concept. *J Clin Sleep Med.* 2014; 10(1):73–8. [PubMed: 24426823]
82. Nandakumar, N., Gollakota, S., Watson, N. Contactless sleep apnea detection on smartphones. Proceedings of the 13th annual international conference on mobile systems, applications, and services; 2015. p. 45-57.
83. Schwab RJ, Badr SM, Epstein LJ, Gay PC, Gozal D, Kohler M, et al. An official American Thoracic Society statement: continuous positive airway pressure adherence tracking systems. The optimal monitoring strategies and outcome measures in adults. *Am J Respir Crit Care Med.* 2013; 188(5):613–20. [PubMed: 23992588]
- *84. Fox N, Hirsch-Allen AJ, Goodfellow E, Wenner J, Fleetham J, Ryan CF, et al. The impact of a telemedicine monitoring system on positive airway pressure adherence in patients with obstructive sleep apnea: a randomized controlled trial. *Sleep.* 2012; 35(4):477–81. [PubMed: 22467985]
85. Kuna ST, Shuttleworth D, Chi L, Schutte-Rodin S, Friedman E, Guo H, et al. Web-based access to positive airway pressure usage with or without an initial financial incentive improves treatment use in patients with obstructive sleep apnea. *Sleep.* 2015; 38(8):1229–36. [PubMed: 25581921]

86. Krakow B, Ulibarri VA, Foley-Shea MR, Tidler A, McIver ND. Adherence and subthreshold adherence in sleep apnea subjects receiving positive airway pressure therapy: a retrospective study evaluating differences in adherence versus use. *Respir Care*. 2016; 61(8):1023–32. [PubMed: 27118876]
87. Weaver TE, Maislin G, Dinges DF, Bloxham T, George CF, Greenberg H, et al. Relationship between hours of CPAP use and achieving normal levels of sleepiness and daily functioning. *Sleep*. 2007; 30(6):711–9. [PubMed: 17580592]
88. American Sleep Apnea Association. [accessed 20.09.16] <http://www.sleepapnea.org/about-asaa.html%3E>
- *89. Redline S, Baker-Goodwin S, Bakker JP, Epstein M, Hanes S, Hanson M, et al. N. Sleep Apnea Patient-centered Outcomes. Patient partnerships transforming sleep medicine research and clinical care: perspectives from the sleep apnea patient-centered outcomes network. *J Clin Sleep Med*. 2016; 12(7):1053–8. [PubMed: 27166300]
90. Strollo PJ Jr, Badr MS, Coppola MP, Fleishman SA, Jacobowitz O, Kushida CA, et al. The future of sleep medicine. *Sleep*. 2011; 34(12):1613–9. [PubMed: 22131593]
91. Shelgikar AV, Durmer JS, Joynt KE, Olson EJ, Riney H, Valentine P. Multi-disciplinary sleep centers: strategies to improve care of sleep disorders patients. *J Clin Sleep Med*. 2014; 10(6):693–7. [PubMed: 24932153]
92. Colvin L, Cartwright A, Collop N, Freedman N, McLeod D, Weaver TE, et al. Advanced practice registered nurses and physician assistants in sleep centers and clinics: a survey of current roles and educational background. *J Clin Sleep Med*. 2014; 10(5):581–7. [PubMed: 24812545]
93. Edinger JD, Grubber J, Ulmer C, Zervakis J, Olsen M. A collaborative paradigm for improving management of sleep disorders in primary care: a randomized clinical trial. *Sleep*. 2016; 39(1):237–47. [PubMed: 26285003]
94. Chai-Coetzer CL, Antic NA, Rowland LS, Reed RL, Esterman A, Catcheside PG, et al. Primary care vs specialist sleep center management of obstructive sleep apnea and daytime sleepiness and quality of life: a randomized trial. *JAMA*. 2013; 309(10):997–1004. [PubMed: 23483174]
95. Watson NF, Rosen IM, Chervin RD. Board of Directors of American Academy of Sleep Medicine. The past is prologue: the future of sleep medicine. *J Clin Sleep Med*. 2017; 13(1):127–35. [PubMed: 27998380]
96. Mulgrew AT, Fox N, Ayas NT, Ryan CF. Diagnosis and initial management of obstructive sleep apnea without polysomnography: a randomized validation study. *Ann Intern Med*. 2007; 146(3):157–66. [PubMed: 17283346]
97. Kuna ST, Gurubhagavatula I, Maislin G, Hin S, Hartwig KC, McCloskey S, et al. Noninferiority of functional outcome in ambulatory management of obstructive sleep apnea. *Am J Respir Crit Care Med*. 2011; 183(9):1238–44. [PubMed: 21471093]
98. Masa JF, Corral J, Pereira R, Duran-Cantolla J, Cabello M, Hernandez-Blasco L, et al. Therapeutic decision-making for sleep apnea and hypopnea syndrome using home respiratory polygraphy: a large multicentric study. *Am J Respir Crit Care Med*. 2011; 184(8):964–71. [PubMed: 21737584]
99. Rosen CL, Auckley D, Benca R, Foldvary-Schaefer N, Iber C, Kapur V, et al. A multisite randomized trial of portable sleep studies and positive airway pressure autotitration versus laboratory-based polysomnography for the diagnosis and treatment of obstructive sleep apnea: the HomePAP study. *Sleep*. 2012; 35(6):757–67. [PubMed: 22654195]
100. Guerrero A, Embid C, Isetta V, Farre R, Duran-Cantolla J, Parra O, et al. Management of sleep apnea without high pretest probability or with comorbidities by three nights of portable sleep monitoring. *Sleep*. 2014; 37(8):1363–73. [PubMed: 25083017]
101. Tan HL, Gozal D, Ramirez HM, Bandla HP, Kheirandish-Gozal L. Overnight polysomnography versus respiratory polygraphy in the diagnosis of pediatric obstructive sleep apnea. *Sleep*. 2014; 37(2):255–60. [PubMed: 24497654]
102. Zia S, Fields BG. Sleep telemedicine: an emerging field's latest frontier. *Chest*. 2016; 149(6):1556–65. [PubMed: 26970035]
103. Hwang D. Monitoring progress and adherence with positive airway pressure therapy for obstructive sleep apnea: the roles of telemedicine and mobile health applications. *Sleep Med Clin*. 2016; 11(2):161–71. [PubMed: 27236054]

- *104. Singh J, Badr MS, Diebert W, Epstein L, Hwang D, Karres V, et al. American academy of sleep medicine (AASM) position paper for the use of tele-medicine for the diagnosis and treatment of sleep disorders. *J Clin Sleep Med*. 2015; 11(10):1187–98. [PubMed: 26414983]
105. Kelly JM, Schwamm LH, Bianchi MT. Sleep telemedicine: a survey study of patient preferences. *ISRN Neurol*. 2012; 2012:135329. [PubMed: 22844614]
- *106. Fields BG, Behari PP, McCloskey S, True G, Richardson D, Thomasson A, et al. Remote ambulatory management of veterans with obstructive sleep apnea. *Sleep*. 2016; 39(3):501–9. [PubMed: 26446115]
107. Abma IL, van der Wees PJ, Veer V, Westert GP, Rovers M. Measurement properties of patient-reported outcome measures (PROMs) in adults with obstructive sleep apnea (OSA): a systematic review. *Sleep Med Rev*. 2016; 28:18–31. [PubMed: 26433776]
108. Piccirillo JF, Gates GA, White DL, Schectman KB. Obstructive sleep apnea treatment outcomes pilot study. *Otolaryngol Head Neck Surg*. 1998; 118(6):833–44. [PubMed: 9627245]
109. Moroni L, Neri M, Lucioni AM, Filipponi L, Bertolotti G. A new means of assessing the quality of life of patients with obstructive sleep apnea: the MOSAS questionnaire. *Sleep Med*. 2011; 12(10):959–65. [PubMed: 22036603]
110. Lacasse Y, Bureau MP, Series F. A new standardised and self-administered quality of life questionnaire specific to obstructive sleep apnoea. *Thorax*. 2004; 59(6):494–9. [PubMed: 15170032]
111. Flemons WW, Reimer MA. Development of a disease-specific health-related quality of life questionnaire for sleep apnea. *Am J Respir Crit Care Med*. 1998; 158(2):494–503. [PubMed: 9700127]
112. MyApnea. [accessed 21.09.16] <https://myapnea.org>
113. Kushida CA, Nichols DA, Holmes TH, Miller R, Griffin K, Cardell CY, et al. SMART DOCS: a new patient-centered outcomes and coordinated-care management approach for the future practice of sleep medicine. *Sleep*. 2015; 38(2):315–26. [PubMed: 25409112]

Practice points

- Patient-centered care in OSA is a valid on ethical grounds, is associated with improved patient outcomes, is necessary to acquire big data for a predictive, preventive, personalized, and participatory medicine approach, and has the potential to improve healthcare team satisfaction.
- Patients with OSA present with different phenotypes; phenotypic presentation may have important therapeutic implications.
- Patient factors including preferences, values, psychosocial factors, health beliefs, and health literacy influence treatment choices as well as adherence to therapy.
- Educational, supportive, and behavioral interventions can improve adherence to positive airway pressure therapy.
- Patient engagement through web-based access to PAP therapy data and other asynchronous telemedicine approaches can improve outcomes.
- A telemedicine pathway including synchronous and asynchronous elements is feasible, is a positive experience for patients, and results in similar outcomes compared with a traditional in-person care model.
- Incorporating patient-centered outcomes in research has the potential to improve patient care.

Research agenda

Future research in this area should include:

- Identifying OSA phenotypes that confer susceptibility to adverse outcomes (e.g., cardiovascular disease)
- Identifying OSA biomarkers for susceptibility to adverse outcomes
- Developing and assessing OSA decision aids
- Assessing the role of spouses/partners in patient decisions regarding OSA treatment
- Assessing the long-term cost-effectiveness of peer buddies on OSA therapy adherence
- Validating sleep mobile apps and wearable sleep monitoring technology
- Assessing electronic messaging, including preference of communication with sleep care team and the effect of text and email automated messages on OSA therapy adherence
- Assessing the current roles and sleep education status of OSA healthcare team members to identify areas for improvement.
- Determining the effect of a healthcare team approach on healthcare provider satisfaction.
- Determining cost-effectiveness of telemedicine approaches
- Developing and validating patient-centered outcomes and incorporating these into studies of healthcare models

Table 1

Applying a patient-centered care approach in obstructive sleep apnea.

Domain	Approaches in obstructive sleep apnea
Patient-specific needs	Physiologic phenotypes Polysomnographic phenotypes Clinical phenotypes
Patient values, preferences, and other factors impacting shared decision-making	Patient preferences Patient psychological factors Patient beliefs and expectations Patient health literacy Decision aids
Patient education and support	Sleep center educational programs Sleep center support programs Behavioral sleep medicine programs Specialist vs. non-specialist care Family/caregiver/partner support Peer support
Patient engagement	Health apps and wearable technology Patient–provider portals Patient access to treatment telemonitoring Patient forums and advocacy
Care coordination, continuity of care, and access to care	Sleep center as patient-centered medical home neighbor Multidisciplinary care teams Primary care involvement Home-based testing and treatment Telemedicine: synchronous and asynchronous
Patient-centered outcomes	Patient-reported outcome measures Patient-centered outcomes research