

SCIENTIFIC INVESTIGATIONS

The lived experience of positive airway pressure therapy in patients with obstructive sleep apnea across the lifespan: a qualitative study

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Study Objectives: Although treatment of obstructive sleep apnea (OSA) with positive airway pressure (PAP) therapy is effective, adherence is often poor. Understanding the patient perspective is needed to inform adherence-promoting interventions. This qualitative study assessed the experiences, preferences, facilitators, and barriers surrounding PAP therapy for the management of OSA in patients from adolescence to older adulthood.

Methods: Eligible participants ages 19 and older were identified from administrative health care claims; adolescent participants ages 12–18 and their parents/caregivers were identified via electronic health records of a tertiary sleep specialty clinic at a large children's hospital. Forty English-speaking patients and 10 parents of adolescents diagnosed with OSA and prescribed PAP therapy completed semistructured 60-minute telephone interviews conducted by a trained facilitator. Common themes and illustrative quotes were identified.

Results: Themes around OSA diagnosis, initiating OSA treatment, learning about OSA/PAP, decision to start PAP, PAP benefits and challenges, and reasons for nonadherence were identified. Participants suggested design and delivery changes to improve PAP devices. Issues unique to adolescents and their parents were discussed.

Conclusions: The unique perspectives of patients regarding PAP therapy should be taken into consideration when developing interventions to increase PAP adherence and improve clinical care. Based on identified themes, opportunities for intervention may exist at all stages of care, from diagnosis to treatment initiation. Involving partners, parents, and other caregivers in PAP therapy may be beneficial for optimizing adherence.

Keywords: treatment adherence, adolescence, older adults, sleep-disordered breathing

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BRIEF SUMMARY

Current Knowledge/Study Rationale: Although treatment of obstructive sleep apnea with positive airway pressure therapy is effective, adherence is often poor. It is important to understand the perspective of patients to develop adherence-promoting interventions.

Study Impact: The themes identified from the qualitative interviews among patients with obstructive sleep apnea across the lifespan illustrate their unique experiences with positive airway pressure. They also provide important information that can be utilized in clinical care and the development of future interventions.

INTRODUCTION

Positive airway pressure (PAP) therapy is a first-line treatment for obstructive sleep apnea (OSA) in adults¹ and is recommended for children if adenotonsillectomy is ineffective or contraindicated.² However, nonadherence to PAP therapy is the most significant barrier to optimizing its effectiveness.¹ Approximately 50% of patients exhibit suboptimal adherence, including inconsistent and low average nightly use.^{3,4} Nonadherence may be even more likely in the most vulnerable of patients; studies show disparities in PAP adherence for minoritized populations and by socioeconomic status.^{5–8} Consequences of inadequately treated OSA are significant, ranging from excessive daytime sleepiness and reduced quality of life to cardiometabolic disease and mortality.^{1,9} Therefore, research is needed to identify key factors impacting PAP use and develop

strategies promoting adherence in individuals across the lifespan.

Factors impacting rates of PAP adherence have been investigated, including patient demographic and disease characteristics; knowledge, beliefs, and expectations around OSA and its treatment; and behavioral and emotional factors.^{3,10–12} Moreover, several interventions have been proposed to promote PAP adherence. Behavioral interventions improve adherence rates by approximately 1 hour per night,⁴ but these strategies are often not generalizable to standard clinical practice and provide only short-term results.¹³

An important step toward developing and/or refining adherence-promoting interventions and optimizing clinical care is to understand patients' experiences with PAP therapy. While limited studies using qualitative methodology have been conducted in patients with OSA, no research exists examining the

use of PAP therapy across the lifespan.¹⁴ Thus, the aim of the current study was to qualitatively assess the experiences, preferences, facilitators, and barriers surrounding using PAP therapy for the management of OSA in patients from adolescence to older adulthood.

METHODS

Study design, participants, and procedures

This qualitative study consisted of individual semistructured telephone interviews with patients diagnosed with OSA who were prescribed PAP therapy. All interviews were audiotaped and transcribed for analytic purposes. Participants received \$100 compensation for completing the study. Interviews were conducted between May and July 2021.

English-speaking patients with OSA and prescribed PAP therapy from each of four age groups were recruited: adolescents (12–18 years) and a parent/guardian; young adults (19–44 years); adults (45–64 years); and seniors (65 years and over). Exclusionary criteria included other medical conditions that may impact sleep (eg, Down syndrome, Prader–Willi syndrome) or cognitive delay/severe mental illness that would preclude participants from responding to interview questions. Adolescents and parents were each interviewed separately.

Two data sources were used to identify eligible patients. The Healthcare Integrated Research Database, a large administrative claims database maintained by Carelon Research (Wilmington, DE), was used as a sampling frame to identify survey-eligible commercial or Medicare Advantage adult patients ages ≥ 19 years with ≥ 1 medical claim with an ICD-10-CM diagnosis code for sleep apnea and ≥ 1 claim with a CPT or HCPCS code for a PAP device during the patient-identification period between February 1, 2019 and January 31, 2020. Eligible adolescents ages 12–18 years prescribed PAP therapy for at least 6 months and a parent/caregiver were identified from a review of electronic health medical records of a tertiary sleep specialty clinic at a large children's hospital.

Patients were contacted by email, mail, and/or telephone call, and if they expressed interest in the study, inclusion/exclusion criteria were reviewed. Informed consent from adult patients and parents/caregivers >18 years and assent from adolescents was obtained prior to scheduling the interview. All study materials were approved by the WCG Institutional Review Board prior to the commencement of study activities.

Interview discussion guide

An interview discussion guide (see supplemental material) was developed by the research team, including sleep subject matter experts, that focused on exploring participants' experiences and perspectives related to their use of PAP therapy. The interview guide was modified to be applicable to adolescent participants and their parents. Questions were developed that targeted domains including the benefits and challenges, risks, and side effects encountered with PAP therapy and beneficial changes to PAP design or delivery. Based on participant responses, the facilitator asked additional probing questions to elicit further

information. Participants also completed a brief demographic questionnaire prior to the interview.

Data analysis

Demographic and clinical characteristic data were tabulated from the questionnaires and presented in aggregated form. A qualitative thematic content analysis using standard methods of inductive, iterative analysis of the interview data was performed.^{15–18} Each transcript was read in its entirety for global assessment by an experienced coder (J.J.S.). Coding of key concepts was conducted on the transcripts, with additional codes added as needed. Codes were then grouped into categories based on common themes. Themes are presented as a summary of participants' statements, with illustrative quotations provided that best reflect the overall statements.

RESULTS

Ten participants from each age group and 10 parents/caregivers of adolescents for a total of 50 participants qualified for the study and completed interviews. Participant demographic and clinical characteristics are summarized in **Table 1** and **Table 2**. Themes identified from qualitative interviews are summarized in **Table 3** and described in detail with illustrative participant quotes.

Obtaining a diagnosis of OSA

Participants viewed their OSA symptoms as serious concerns that impacted their quality of life. The primary complaints that led to further testing and ultimately a diagnosis of OSA were snoring and excessive daytime sleepiness. Participants were often told by family members that they snored and held their breath while they slept, which led them to want to understand the cause of these issues. Other symptoms mentioned by participants included headaches and acid reflux. Most adolescent participants had one or more comorbid medical conditions (eg, obesity, asthma) that influenced the recommendation to obtain a sleep study.

Illustrative participant quotes

- “Snoring, at first thought I had narcolepsy because I kept dozing off during the day. Constant fatigue and tired.” Young Adult 19–44
- “My husband told me I stopped breathing at night.” Adult 45–64
- “I was really tired, struggled staying awake. . . . My wife said I snored.” Adult 45–64
- “I had heartburn, pressure and would wake up gasping for breath.” Senior 65+
- “I had headaches and would always want to take a nap; didn't have any energy.” Adolescent 12–18
- “He's a very deep snorer. Kind of gasped for air when he was sleeping. So they went ahead and had him tested.” Parent of Adolescent 12–18

Many participants expressed relief following their diagnosis of OSA. That there was a treatment option for their symptoms was welcoming for many participants. However, for some participants, the relief was accompanied by other emotions

Table 1—Participant demographic characteristics.

	Adolescents (12–18 years)	Parents of Adolescents	Young Adults (19–44 years)	Adults (45–64 years)	Seniors (>65 years)
Participants, n	10	10	10	10	10
Female, n (%)	1 (10.0)	10 (100.0)	5 (50.0)	6 (60.0)	4 (40.0)
Age (years), mean (SD)	15.8 (1.9)	–	39.4 (4.7)	57.7 (5.4)	70.1 (4.2)
White, non-Hispanic, n (%)	5 (50.0)	6 (60.0)	7 (70.0)	9 (90.0)	9 (90.0)
Marital status, n (%)					
Single	10 (100.0)	1 (10.0)	5 (50.0)	2 (20.0)	2 (20.0)
Married	0 (0.0)	8 (80.0)	3 (30.0)	6 (60.0)	5 (50.0)
Other	0 (0.0)	1 (10.0)	2 (20.0)	2 (20.0)	3 (30.0)
Adult education level, n (%)					
High school degree or equivalent	–	3 (30.0)	2 (20.0)	2 (20)	3 (30.0)
Some college	–	5 (50.0)	2 (20.0)	3 (30)	3 (30.0)
Bachelor or graduate degree	–	2 (20.0)	6 (60.0)	5 (50.0)	4 (40.0)
Adolescent education level, n (%)					
Grades 7–10	3 (30.0)	–	–	–	–
Grades 11–12, college freshman	5 (50.0)	–	–	–	–
Not attending school	1 (10.0)	–	–	–	–
Other	1 (10.0)	–	–	–	–
Employment status, n (%)					
Employed full-/part-time	–	4 (40.0)	8 (80.0)	7 (70.0)	3 (30.0)
Disabled, retired, homemaker	–	6 (60.0)	2 (20.0)	3 (30.0)	7 (70.0)

SD = standard deviation.

including fear of what the diagnosis meant and concern with having to use PAP therapy as a solution. Emotions around having to use PAP therapy ranged from acceptance (most participants) to resentment and concerns around how PAP would impact their lifestyle (a few participants). Some of the participants with concerns cited claustrophobia and a general concern about wearing a mask while they slept.

Illustrative participant quotes

- “It was a bittersweet moment ... because for me. ... I knew something was wrong, and I didn’t know what it was. Then I found out what was wrong ... so I knew I wasn’t crazy.” Young Adult 19–44
- “I was glad that I finally got diagnosed with something that I knew that there was a way to make me feel better during the day and less lethargic, and could sleep better. So I was excited.” Young Adult 19–44
- “Relieved and fearful. I am claustrophobic so having something on my face made me quite anxious.” Adult 45–64
- “It was good to know it wasn’t just me ... That it was something more underlying.” Adult 45–64
- “It didn’t bother me. I figured I was going to be leading a better life. I thought it was for my best interest.” Senior 65+
- “Surprised but in a sense also relieved because I knew this is why I’ve been so tired. Also sucks because nobody wants to sleep with something on their head ... from

what I remember I was a little bit down about it as well, kind of like ‘why does this have to happen to me’ kind of thing?” Adolescent 12–18

Initiating treatment for OSA

Parents reported concern about the overall health and growth of their children as a motivator for treatment. Some participants had heard stories of people who had died in their sleep and connected this with OSA, motivating treatment initiation. Participants noted that the sleep study results helped them to understand that OSA caused them to stop breathing while they slept. They reported learning about the number of “episodes” they had during the night or whether they had “severe” OSA. Few participants endorsed a detailed understanding of how PAP worked, but most noted that it forced air into their airway and this somehow would allow them to be less tired. A few participants who trialed PAP during the sleep study said they woke up “refreshed” for the first time in a long time. These factors combined with symptoms experienced led participants to initiate PAP therapy without much discussion or debate.

Illustrative participant quotes

- “He said that it was probably more beneficial for me, but he really didn’t go into the medical details.” Young Adult 19–44

Table 2—Participant clinical characteristics.

	Adolescents (12–18 years)	Parents of Adolescents	Young Adults (19–44 years)	Adults (45–64 years)	Seniors (>65 years)
Participants, n	10	10	10	10	10
Age diagnosed with sleep apnea (years), mean (SD)	13.2 (3.7)	12.4 (4.0)	35.3 (4.2)	52.7 (8.1)	57.6 (8.4)
Sleep apnea duration (years), mean (SD)	2.6 (2.1)	3.4 (2.5)	4.1 (3.2)	5.0 (4.9)	12.5 (9.1)
Types of health care providers currently see for sleep apnea (yes), n (%) ^a					
Primary care physician	3 (30.0)	4 (40.0)	2 (20.0)	7 (70.0)	4 (40.0)
Pulmonologist	3 (30.0)	5 (50.0)	5 (50.0)	2 (20.0)	4 (40.0)
Ear, nose, and throat physician	1 (10.0)	1 (10.0)	1 (10.0)	1 (10.0)	0 (0.0)
Orthodontist	0 (0.0)	0 (0.0)	0 (0.0)	1 (10.0)	0 (0.0)
Other health care provider	5 (50.0)	4 (40.0)	3 (30.0)	2 (20.0)	4 (40.0)
Currently use PAP therapy (yes), n (%)	9 (90.0)	9 (90.0)	10 (100.0)	10 (100.0)	10 (100.0)
Length of time used PAP therapy, n (%)					
Valid n	9	9	10	10	10
6 mo–<12 mo	2 (22.2)	2 (22.2)	2 (20.0)	0 (0.0)	1 (10.0)
1 year–<2 years	3 (33.3)	2 (22.2)	2 (20.0)	5 (50.0)	0 (0.0)
2 years–<5 years	3 (33.3)	3 (33.3)	3 (30.0)	2 (20.0)	0 (0.0)
5 years or more	1 (11.1)	2 (22.2)	3 (30.0)	3 (30.0)	9 (90.0)
Used other therapy for sleep apnea (yes), n (%)	1 (20.0)	2 (20.0)	2 (20.0)	1 (10.0)	2 (20.0)
Other therapies used (yes), n (%) ^a					
Valid n	1	2	2	1	2
Oral appliance	0 (0.0)	0 (0.0)	0 (0.0)	1 (100.0)	1 (50.0)
Surgery	0 (0.0)	1 (50.0)	0 (0.0)	0 (0.0)	1 (50.0)
Breathing mask	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (50.0)
Nasal decongestants or other medications	1 (100.0)	2 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)
Weight loss	0 (0.0)	0 (0.0)	1 (50.0)	0 (0.0)	0 (0.0)
Positional therapy	0 (0.0)	0 (0.0)	1 (50.0)	0 (0.0)	0 (0.0)
Other	0 (0.0)	0 (0.0)	1 (50.0)	0 (0.0)	0 (0.0)

^aCategories are not mutually exclusive. SD = standard deviation, PAP = positive airway pressure.

- “Bad things can happen and it will help me prolong my life because of less strain on my heart.” Adult 45–64
- “Waking up for the first time after having the therapy through the night I felt invigorated because it felt like I hadn’t slept forever and that was my first good night’s sleep I had in years.” Senior 65+
- “I insisted that I wasn’t going home without it!” Senior 65+
- “My father actually, he told me the severity of sleep apnea. ... So he really tried to stress the severity of it to me at the beginning.” Adolescent 12–18

Learning more about OSA and PAP therapy

Few participants reported researching PAP therapy, though a few sought more information about OSA. Participants stated

they searched “sleep apnea” and relied on perceived trusted sources for information. Those with little or no awareness of OSA or PAP therapy relied on their doctor or home health care workers to answer questions or provide information. Approximately half of the participants reported having a family member who had OSA or used PAP and stated that this family member was a primary source of information. No one reported using social media as a source of information for decision-making or education around OSA or PAP.

Illustrative participant quotes

- “I personally got to see someone go through it instead of actually having to read or go through it and do my own research. “Young Adult 19–44

Table 3—Primary themes and descriptions from qualitative interviews.

Primary Theme	Description
Obtaining a diagnosis of OSA	<ul style="list-style-type: none"> OSA symptoms were serious concerns that impacted quality of life and a sleep study was a way to understand the cause of these issues Mixed emotions following OSA diagnosis included relief, fear, and resentment
Initiating treatment for OSA	<ul style="list-style-type: none"> Health and well-being motivated treatment Participants endorsed a limited understanding of PAP therapy
Learning more about OSA and PAP therapy	<ul style="list-style-type: none"> Family members were a primary source of information about OSA and PAP therapy
Decision to start PAP therapy	<ul style="list-style-type: none"> PAP therapy was presented as the primary treatment option Adolescents and parents were more likely to be referred for a surgical consultation or to be recommended weight loss Many participants followed their doctor's direction to initiate PAP Young adults and adolescents discussed PAP therapy with parents
Benefits and challenges of using PAP therapy	<ul style="list-style-type: none"> Participants noted benefits of PAP including better sleep, less daytime sleepiness, and decreased stress A primary barrier endorsed was adjusting to PAP
Reasons for nonadherence	<ul style="list-style-type: none"> Mask discomfort was commonly reported and influenced PAP usage Other problems identified included resupply and insurance coverage, device cleaning, and humidifier adjustment difficulties
PAP design and delivery changes	<ul style="list-style-type: none"> Suggestions to improve PAP included a smaller device; more comfortable mask; easier to clean; and a longer, more flexible hose
Issues unique to adolescents and their parents	<ul style="list-style-type: none"> Adolescents were more likely to routinely need to use PAP in more than one location Parent-adolescent conflict around PAP was reported

OSA = obstructive sleep apnea, PAP = positive airway pressure.

- “I googled it, but obviously, as a teacher, I know credible sources. So I looked at a lot of research-based information. ... Because I mean, when a doctor is talking to you, it's overwhelming, especially when you find out you have something that you don't know anything about. ... So just understanding what my body was doing and understanding what it's doing to me, and then understanding how it can cause you to lose years of your life.” Young Adult 19–44
- “Not [regarding] the therapy per se, but I did do a little research about the condition I had. I looked it up on Google. My school, they tell us stuff on how to find reliable sources, so I found a nice reliable source to get my information from.” Adolescent 12–18
- “I was aware of it because both of my parents have it. I knew what it was but I wasn't sure of the challenges that were going to come with it.” Adolescent 12–18

Decision to start PAP therapy

Once participants received their OSA diagnosis, PAP therapy was reportedly presented as the only treatment option. Most participants said there were no other treatment options mentioned by their doctor. A few participants were told about a dental appliance but stated they were not given details. Adolescents were more likely to receive a referral to explore surgical options for treating OSA such as having tonsils removed. Very few adult participants were told about surgical options, and none considered surgery.

Adolescent participants and their parents were more likely to be aware of the benefits of weight loss in treating OSA. Several parents mentioned that weight was a factor in their child's diagnosis but that weight loss was recommended *along with* PAP therapy and not instead of it. The few adult participants who were aware of the impact of weight loss said it was not a recommendation by their doctor during their treatment discussions but it was something brought up during subsequent discussions or something they learned from other sources.

Illustrative participant quotes

- “There were no options. The doctor said this was the best course of action. CPAP was the right way to go.” Senior 65+
- “Doctor talked about going through the dental route and getting a mouth guard. It was more expensive and not covered by insurance.” Adult 45–64
- “They also informed me that there was a surgery that I could do that could help eliminate it without having to use the CPAP, but they can't guarantee that it's going to be a hundred percent.” Young Adult 19–44
- “I looked it up online and learned that losing weight might help.” Senior 65+
- “Obviously the biggest thing would be weight loss but other than that, CPAP was pretty much what you're going to do. Just that you need to exercise, work on my diet, and if I were able to lose an excess amount of weight that I could have avoided the CPAP, but it was not likely in a short amount of time to do so, so the CPAP was definitely recommended.” Adolescent 12–18

After talking with their doctor after the sleep study, participants reported that there was relatively little decision-making left to be done. Many participants said the decision to initiate PAP therapy was made by their doctor and that they were “following orders.” Some participants discussed the treatment with their partner but said that, ultimately, they independently made the decision. Some young adults discussed whether to initiate PAP therapy with their parents. Parents of adolescent participants tended to drive the decision with their child, although the level of involvement varied with the age of the child: younger children followed the instructions of their parents. Adolescents were more involved in the decision as parents realized adherence to treatment was dependent on their willingness to use the equipment.

Insurance coverage and cost discussions took place at the point of securing the PAP equipment and were not typically done with the doctor. Insurance coverage and cost varied across participants from full coverage to no coverage until deductibles were met. Parents of adolescent participants reported that PAP therapy was fully covered by their insurance as long as minimum usage times were met.

Illustrative participant quotes

- “Talked it over with my parents and got their thoughts on it. My mom very much advocated for finding somehow to fix whatever was going on with me sleep-wise.”
Young Adult 19–44
- “Just my wife. And I said, ‘I’m going to be wearing a mask at night.’ And of course, there was a little humor in that and she goes, ‘Well, we’ll see how it works out.’”
Senior 65+
- “No, when my doctor suggested I do it that’s all there was to it. I didn’t talk to anyone about it. But it didn’t matter. I was going to do it anyways.” Senior 65+
- “Talked to my mom and the doctor, and it was the best thing for me, so I just went through with it.” Adolescent 12–18
- “We both talked about it. I have sleep apnea myself, and ever since I started my machine, he sees how I’ve been doing so much better, so he was willing to try and see if that helped him as well. But it was a mutual thing between both of us to make sure that he got whatever he needs.” Parent of Adolescent 12–18

Benefits and challenges of using PAP therapy

Participants stated that no side effects or negative effects of PAP therapy were mentioned by doctors. The focus of the discussion with doctors was on the dangers of OSA and the benefit of PAP therapy. The overall experience of using PAP was positive for most participants. They endorsed better sleep, less daytime sleepiness, and reduced stress around nighttime breathing issues. For adolescent participants and their parents, it was initially hoped that PAP would help with comorbid conditions although reported outcomes were mixed.

The most commonly reported challenge was “getting used to” PAP therapy. Difficulties included adjusting to the mask and air pressure while sleeping. Some participants adapted

more easily while others stated they never became comfortable. Others said exploring different types of masks and ensuring optimal fit made a difference in adapting to therapy. Those participants with difficulty often reported taking the mask off at night, either consciously or subconsciously.

Illustrative participant quotes

- “It’s amazing! I take my machine with me wherever I go. I don’t go a day without it. If I sleep without it, my throat hurts, I’m tired, I feel just blah.” Young Adult 19–44
- “It took adjusting to. But I don’t sleep as well without it. I find that I am choking without it.” Senior 65+
- “It helps a bunch. I’ll use it and there would be some nights where like I wouldn’t put it on and you feel it. The next day you have headaches all day and no energy, but like when you have it, you’re good all day.” Adolescent 12–18
- “At first it was super weird to be using. You know? Because it was my first time ever using one and I wasn’t used to having extra air, but then after about two or three weeks of using it, it just became a habit.” Adolescent 12–18

Reasons for nonadherence

Discomfort with the mask was a commonly reported reason for nonadherence to PAP. Some participants were able to switch the mask type and increase their PAP usage, while other participants continued to search for an option that better fit their needs. Some participants said the home health company that provided their PAP device reviewed mask options thoroughly and worked with them to find the right design. Other participants were not aware that there were options around masks and struggled to make what they were given work for them.

Illustrative participant quotes

- “If I’m getting sort of annoyed with one position, it’s nice to be able to swap to the other headgear.” Young Adult 19–44
- “They let me try a few masks to find the one I was most comfortable with.” Adult 45–64
- “I originally got full face mask and I changed to the nose. . . . The facemask didn’t have all the extra headgear on it and the gel pack cushions and stuff like that. It was just much more comfortable.” Senior 65+
- “It used to cover your nose, cover your mouth. And it was very cumbersome. Now it just goes underneath your nose and it feeds air up through your nose. So your mouth it’s not affected at all, which was, to me, it was a good improvement.” Senior 65+
- “We switched. I first started off with the nose one, hated the nose one, and then I just got the straight up cup over the nose and mouth one, and that one has definitely been a lot better.” Adolescent 12–18
- “There was, like a tech person I want to say. When we did get the machine, she kind of gave us several options of masks and stuff, so she was extremely helpful.” Parent of Adolescent 12–18

While most participants said they did not have problems with their PAP device, if they did experience problems, these were reportedly rarely discussed with physicians or the home health care equipment specialists. The problems noted most frequently involved resupply and insurance coverage issues, difficulties cleaning the device, and adjusting the humidifier. Insurance coverage issues primarily centered around coverage for supplies. Supply issues included difficulties communicating with home health care equipment companies, which participants felt were difficult to communicate with, did not return phone calls, and were described as “dismissive” and “rude.” Other participants mentioned that suppliers often did not offer online reordering or adjustments of orders and required that everything be done via telephone. Adolescents reported that their parents were the ones who dealt with the equipment companies and supply issues. With regards to cleaning the PAP machine, participant issues included the need for distilled water, having too many pieces to clean, and the time-consuming nature of the task. A few participants mentioned they felt the device was too difficult to take apart. Frequency of cleaning varied, with one respondent stating they never cleaned their device, while other participants found a cleaning routine that worked for them. Finally, some participants felt the humidity level was hard to set or adjust and gave an example that setting the humidity level too high caused water to build up in the hose, prohibiting use.

Illustrative participant quotes

- “[Company that provides supplies] is one of the rudest companies I’ve ever worked with in my life. Unfortunately, it’s the only company in the area and no, I do not respect them, do not like them, do not like their attitude, they were very hateful, and I do not care for them at all.” Adult 45–64
- “They keep changing how you’re supposed to order stuff and it’s never consistent. And now they have an app, which you can’t really do much with other than push the button. But sometimes I want to change up my supplies, because I do use the two different headgear styles, and I assume that means that I’d have to call somebody, and I never like calling people. So I just end up reordering the same stuff and making it work.” Young Adult 19–44
- “I have not gotten any new supplies. We are having trouble with insurance. My mom is working on it.” Adolescent 12–18

PAP design and delivery changes

Most participants agreed that PAP devices needed improvement. Suggested improvements included:

- Device: smaller; easier to travel with; take up less room on nightstand; portable power source
- Mask: secure without as many straps; increased comfort; does not leave marks; smaller and more compact nose cushion that does not rub the lips or mouth
- Cleaning: easier to clean; fewer parts to clean
- Hose/tubing: longer hose that does not tangle or a hose that flexes when sleeping position changes; a way to get

the benefit of air pressure without being hooked up to a machine (no hose or tubing)

Illustrative participant quotes

- “I mean it’s just a pain in the butt to constantly take everything apart and put it in the sink and scrub it. ... It was just a hassle.” Young Adult 19–44
- “Make it a little smaller. It takes up most of my nightstand. It could be half the size.” Young Adult 19–44
- “If there was a way to not have to wear a face mask. So something wasn’t on your face.” Adult 45–64
- “Make it easier to sleep in different positions without leaking.” Senior 65+
- “I have to have a separate bag when you travel. If I’m going on a soccer trip, because I play competitive soccer, it’s kind of like, not embarrassing, but it’s another thing I have to bring along which kind of stinks, but, if I could put it in my bag that would be a great thing.” Adolescent 12–18
- “I would try to make it a little bit more comfortable for what’s sitting on your face, just so you have a little bit more movement and you’re not waking up with a whole bunch of marks on your face and you can sleep in the way that you want to, and then I would definitely add more length to things so that you have that room to move.” Adolescent 12–18
- “If they have something different, to make them more comfortable than wearing a big old mask, if there was something more comfortable for the children, I think that’s the only thing. The masks are kind of annoying and they slip off.” Parent of Adolescent 12–18

Issues unique to adolescents and their parents

Adolescent participants were more likely to have a need to use their PAP device in more than one location regularly. A few adolescent participants and their parents mentioned having to transport the device when they regularly stay with another family member, for example, when switching between the homes of divorced parents. The participants mentioned that having a device that was more portable, or having two devices, currently not covered by insurance, would facilitate greater usage.

Illustrative participant quotes

- “His father lives in a different state. So, when he first got on it, I wouldn’t let him go anywhere with his CPAP, I wanted him to stay home, so it caused a little conflict with that because I wouldn’t let him go out of state on CPAP.” Parent of Adolescent 12–18
- “There was times where ... we had to figure out how to move the machine back and forth. ... And so that was happening for I think a month or two, because my sister and I were just alternating our kids because of our work schedule.” Parent of Adolescent 12–18

Conflict around PAP use was sometimes reported. Parents of adolescents felt they understood the challenges surrounding use of the device and said their children were doing what they could to adapt. For older adolescent participants, their parents saw

this as a responsibility their teens needed to understand and felt that while they could provide support, they had little influence over making them adhere to treatment.

Illustrative participant quotes

- “It’s mainly just my mom telling me to use it more and me saying no.” Adolescent 12–18
- “She [mom] always reminds me which I really appreciate it. ‘Hey, why don’t you put your CPAP in?’ Most of the nights I usually say okay and get my CPAP on.” Adolescent 12–18
- “He’s like a little grown man so he’s got all his stuff situated and he does a good job, actually.” Parent of Adolescent 12–18

DISCUSSION

This qualitative examination of perceptions around OSA and PAP therapy in patients across the lifespan identified several themes that may be used to inform adherence interventions and improve clinical care. Enhancing the patient experience by providing education and support from the initial consultation with a medical provider, during diagnostic testing, and through the decision to initiate PAP therapy may be helpful. Prior research has shown that patients who receive better education regarding OSA and PAP therapy are more likely to perceive the risk of untreated OSA and adhere to PAP.¹⁹ Moreover, greater adherence during the first month of PAP therapy demonstrated better subsequent adherence than patients who struggled to use the device early in treatment,^{20,21} suggesting that early, intensive efforts to help patients may have longer term benefits.

When deciding whether to pursue PAP treatment, senior and adult participants consulted with their partners, young adults spoke with their parents, and parents made the decision with and/or for their children. Therefore, including partners, parents, and other family members in discussions around PAP may help patients make informed decisions and potentially have benefits for adherence if they feel supported in their treatment choice. These findings are similar to prior qualitative studies in adolescents that highlighted the need for family support²² and in adults and seniors where partner involvement was highly regarded as beneficial to promote PAP use.^{23,24} Indeed, a couples-based sleep health adherence-promotion intervention, We-PAP, is currently being trialed in older adults on the premise that partners may have an important impact on treatment seeking and adherence rates.²⁵ The Improving CPAP Adherence Program intervention successfully sustained improved PAP adherence for 6 months posttreatment utilizing a shared decision-making and caregiver engagement framework to involve patients and caregivers in adherence promotion.²⁶ Similar strategies could likely be applied to adolescents and their parents. Moreover, in-person and telephone peer support programs can improve PAP adherence and patient satisfaction.²⁷

Participants identified many benefits of using PAP, including improved daytime symptoms. However, significant challenges

were also identified, including adjusting to the mask and air pressure sensations during sleep. In fact, mask discomfort was a commonly cited reason for nonadherence. Prior qualitative assessments of both adolescents with OSA and veterans nonadherent to PAP found similar reports of physical challenges.^{22,28} Notably, more barriers than benefits tended to be reported for individuals with poorer adherence.²² Despite recent technological advances in PAP devices,²⁹ participants in the current study identified areas for continued improvement with regards to PAP design and delivery. Specific suggestions included increased portability, comfort, and ease of cleaning and use. While studies have shown that PAP machine and mask features are not the primary drivers of adherence rates,^{10,30} these factors may nonetheless be important for patients. Commonly reported barriers, including difficulties with cleaning and maintaining the device, and challenges with equipment resupply should be routinely addressed in clinical care.

Unique to the adolescent–parent dyads, conflict around PAP use was sometimes reported. Parents perceived PAP use as the child’s responsibility and felt they were unable to force adherence. Yet, studies have shown that adolescents who receive practical support from parents have higher rates of PAP adherence.³¹ Helping parents of adolescents to identify strategies to support their child may be beneficial for improved adherence. Further, approaches to improve parent–child communication and reduce conflict around PAP usage may be beneficial to incorporate in adherence promotion interventions.

Strengths of the current study include a relatively large sample size for qualitative research and inclusion of individuals across the lifespan, including parents of adolescents. However, several limitations must be acknowledged. Specifically, we were not able to obtain objective adherence data from participants nor were we able to stratify participation across varying levels of adherence. While the sample included a wide age range, patients <11 years were excluded: it is likely that younger children and their parents experience unique barriers that should be examined in future research. The recruitment methodology may have resulted in a selection bias, such that those participants who chose to participate may not be representative of the general population of PAP users. Recall errors may also have occurred, given that the average duration of OSA diagnosis ranged from approximately 3 to 12 years across the age span. Further, the current sample was not demographically representative, and, given the known disparities in adherence by racial/ethnic and socioeconomic status,^{5,6} future research focused on understanding the unique barriers experienced by minoritized and vulnerable groups is recommended.

PAP nonadherence is extremely common across the lifespan, and inadequately treated OSA increases risk of morbidity and mortality.¹ Behavioral PAP adherence-promoting interventions show promise,⁴ but additional work is needed to develop individualized and tailored interventions for different age groups across all stages of care.³² To our knowledge, this is the first study to qualitatively assess the lived experience of OSA and PAP therapy in individuals across the lifespan. Findings suggest that early patient education and support, engaging family members in decision-making, and acknowledging and collaboratively

addressing challenges related to PAP therapy may benefit patients and improve adherence. Further research is recommended evaluating the impact of incorporating these strategies into interventions for patients with OSA. The current study advances our understanding of the patient experience of using PAP across the lifespan, with a goal of informing future adherence promotion efforts and optimizing clinical care for patients with OSA.

ABBREVIATIONS

OSA, obstructive sleep apnea
PAP, positive airway pressure

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