

Original Article

Caregiver support and positive airway pressure therapy adherence among adolescents with obstructive sleep apnea

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Abstract

Introduction: Positive airway therapy (PAP) adherence rates are suboptimal among adolescents with obstructive sleep apnea (OSA) and strategies to increase PAP adherence is a clinical priority. This study evaluates if caregiver support is associated with PAP adherence rates among adolescents with OSA.

Methods: We conducted a retrospective study and evaluated PAP adherence rates among adolescents with OSA from 2012 to 2017. Adherence was measured as continuous variables: average PAP usage (minutes per night) and average PAP usage >4 hours/night (% of all nights). We evaluated if adolescents with OSA who were receiving practical caregiver support with PAP had higher adherence than adolescents with OSA without caregiver support.

Results: One hundred and seven adolescents with OSA (mean age=14.1±2.5 years, 64.5% male, mean BMI percentile=89.0±21.8) seen between January 2012 and August 2017 at our institution were included. In this study, 60.7% (n=65) of adolescents with OSA were receiving practical caregiver support with PAP therapy. Adolescents with OSA receiving practical caregiver support with PAP used therapy for a significantly greater duration each night compared to adolescents who were not receiving practical caregiver support (298.5±206.7 versus 211.9±187.2 minutes; P=0.02). Greater time since the initial PAP prescription was independently associated with PAP adherence.

Conclusion: Focusing on PAP adherence early may help adolescents with OSA incorporate therapy into their nightly routine, which may improve adherence and lead to improved health outcomes in adolescents with OSA. Practical caregiver support may be an essential component of ensuring optimal PAP adherence among adolescents with OSA.

Keywords: Adherence; Adolescents; Obstructive sleep apnea; Paediatrics; Positive airway pressure

Obstructive sleep apnea (OSA) is characterized by snoring, recurrent partial (hypopneas), or complete obstruction (apneas) of the upper airway, frequent intermittent oxyhemoglobin desaturations, and sleep fragmentation (1). The prevalence of OSA is 1 to 4% in otherwise healthy youth, but is reported to

occur in 25% of obese youth (2). If left untreated, OSA is associated with adverse neurocognitive, metabolic and cardiovascular consequences (3–6). Moreover, untreated OSA results in a 226 per cent increase in health care utilization compared to children without OSA (7). OSA is commonly associated with

adenotonsillar hypertrophy (8) and an adenotonsillectomy (AT) is typically the first line of treatment in young children with a normal body mass index (BMI) (9). However adenotonsillar hypertrophy is not always the most significant risk factor for OSA, especially among adolescents with comorbidities such as obesity (5) and craniofacial malformations (10). As a result, AT surgery is not successful in resolving OSA in these groups of adolescents (11–13) and positive airway pressure (PAP) is increasingly used as treatment for adolescents with OSA (14,15).

Although PAP is effective in treating OSA, adherence in paediatric populations is suboptimal, ranging between 30 to 60 per cent (16). PAP adherence in paediatric patients with OSA is associated with sociodemographic factors such as maternal education, race, sex, patient age, and family stability (17–19). Recent qualitative data show adolescents with OSA actually desire caregiver support with PAP therapy (20); however, it is unclear how caregiver support affects PAP adherence rates among adolescents. Caregiver support is associated with better treatment adherence among adolescents with other chronic conditions (e.g., asthma, type 1 diabetes) (21,22). While caregiver support can be provided both practically (e.g., placing PAP mask on the child) and emotionally (e.g., positive encouragement to use PAP), practical support has been shown to be more beneficial for treatment adherence in other disease groups (23). Understanding how caregiver support is associated with PAP adherence is important for paediatric clinical teams optimizing management of adolescents with OSA, an age group that is particularly vulnerable to treatment nonadherence (24).

The primary objective of the current study was to compare PAP adherence rates in adolescents with OSA who were stratified into two groups: 1) PAP users with caregiver support; 2) PAP users without caregiver support. The secondary objective was to evaluate factors associated with PAP adherence in adolescents with OSA.

METHODS

Study population

We retrospectively reviewed the charts and polysomnogram (PSG) data of adolescents (age 10 to 18 years) who were followed clinically for OSA and prescribed PAP at The Hospital for Sick Children in Toronto, Ontario. This study was approved by the Research Ethics Board at the Hospital for Sick Children, a tertiary care centre in Toronto, Canada. Patient inclusion and exclusion criteria are described below:

Inclusion criteria

We included patients between the ages of 10 and 18 years. This age range was selected as it encompasses the World Health Organization definition of an adolescent (25). We included adolescents with OSA who were consecutively referred,

diagnosed by a polysomnogram (PSG), followed at our institution, were on PAP therapy between January 2012 and August 2017, had a PAP download data available and had been prescribed therapy for a minimum of 3 months.

Exclusion criteria

We excluded patients with central sleep apnea or hypoventilation in order to focus on OSA, the most common sleep disorder requiring PAP therapy in our institution.

Caregiver support definition and group classification

Patients receiving practical caregiver support with PAP therapy were classified as 'PAP users with caregiver support'. Practical support encompasses receiving help through tangible acts and services (26) (e.g., administering PAP therapy to the child). Practical caregiver support with PAP is documented in the notes of the patient's medical record by the clinical team (e.g., respiratory therapist) who ask about caregiver support with therapy, and was again confirmed by the clinical team and the respiratory therapist (AB) dedicated to the PAP program at our institution for the purpose of this study. The respiratory therapist is responsible for following all patients prescribed PAP. Patients who were not receiving practical caregiver support with PAP therapy were classified as 'PAP users without caregiver support'.

Study procedures and measurements

Patients were typically referred into the sleep disorders clinic with a history of snoring from local weight management clinics, specialist clinics within our institution, and from community paediatricians. OSA was diagnosed using the gold standard PSG. PSGs were conducted and scored according to the American Academy of Sleep Medicine (AASM) guidelines (27) using Natus Sleepworks system (Natus Medical Incorporated, California) data acquisition, and analysis systems. Sleep architecture was assessed by standard techniques (27). All respiratory events were scored according to the AASM scoring guidelines by a registered certified polysomnographic technician (28). All sleep studies were reviewed and interpreted by experienced paediatric sleep physicians. OSA was diagnosed according to the OAH1, the number of obstructive apneas, mixed apneas, and obstructive hypopneas per hour during sleep.

Demographic and clinical characteristics of the cohort were obtained from the clinic notes in electronic medical records. BMI percentile was calculated according to age and sex specific growth curves using height and weight. BMI percentile was used to clinically define patients as obese (≥ 95 th percentile) for age and sex (29).

PAP protocol

Paediatric sleep physicians prescribed PAP to patients diagnosed with OSA as per standard of care at our institution. A formal

overnight titration study was performed in patients to determine the pressure setting for PAP. In the clinic setting, patients received a mask fitting and an air pressure trial with the respiratory therapist. The respiratory therapist also explained how to use PAP to both patients and their caregivers and provided complementary educational materials (e.g., PAP information booklet). Modes of PAP therapy used to treat OSA included: auto-titrating continuous positive airway pressure (APAP), continuous positive airway pressure (CPAP), and Bi-Level PAP (BPAP).

The institution's respiratory therapist made a phone call to the patient/patient's caregivers within 2 to 4 weeks of initiating therapy, to troubleshoot any barriers to PAP usage. The first respiratory therapist phone call following PAP initiation, at routine clinic appointments, sleep studies, and with any recurrence of OSA symptoms or changes in clinical status. At this time, the clinical team also asked whether or not the patient was receiving practical caregiver support with PAP therapy. Patients were seen in regular PAP follow-up clinic appointments approximately 3 months after PAP therapy was initiated and every 6 to 12 months thereafter with the respiratory therapist and paediatric sleep physician. PAP adherence was measured objectively using data downloads from the devices. Data were downloaded with the device data card or remotely from PAP devices with built-in cellular connectivity. For this study, PAP adherence data from the most recent download were utilized.

For this study, PAP adherence was assessed as a continuous variable for a minimum of 30 consecutive nights. Continuous variables were as follows: 1) average PAP usage (minutes per night) and 2) average PAP usage >4 hours/night (% of all nights). PAP adherence was not measured as a categorical variable (adherent versus nonadherent) as there is no definition of PAP adherence in paediatric populations.

Statistical methods

Descriptive statistics of both groups of PAP users were evaluated and compared. A chi-square test was used for categorical variables and Student's t-test for continuous variables. Multiple linear regression models were used to examine the relationship between caregiver support (yes or no) and PAP adherence (assessed as a continuous variable) while controlling for the following covariates: PAP mode (CPAP, BPAP, or APAP), age (years), presence of obesity (yes or no) and AT status (yes or no), time since PAP prescribed (years), and cognitively capable of administering PAP independently (yes or no). Unless otherwise specified, data were reported as mean and standard deviation (SD). Histograms and Kolmogorov-Smirnov tests were used to examine normality of distribution. Two-tailed statistical significance level was set at $P \leq 0.05$. Data were analyzed using SPSS version 25.0 (SPSS Inc., Chicago, IL).

RESULTS

One hundred and seven adolescents (mean age=14.1±2.5 years, 64.5% male, mean BMI percentile=89.0±21.8) with OSA from the Hospital for Sick Children seen between January 2012 and August 2017 were included in this study. Of the entire study cohort, PAP was used for an average of 264.5±202.9 minutes per night and for ≥4 hours per night on 48.6±37.8% of all nights recorded for this study period. In this study, 60.7% (n=65) of adolescents with OSA were receiving practical caregiver support with PAP therapy and were classified as PAP users with caregiver support.

Detailed patient demographic and clinical characteristics of each group are described in Tables 1 and 2. A greater percentage of PAP users in the caregiver support group had AT surgery (53.3 versus 46.7%; $P=0.03$). The time since PAP was prescribed was also longer in PAP users with caregiver support compared to PAP users without caregiver support (2.6±2.5 versus 1.6±1.7 years; $P=0.02$) PAP users in both groups had various comorbid conditions. In the PAP users with caregiver support group (n=65), adolescents had coexisting obesity alone (n=21), trisomy 21 (n=19), Prader Willi syndrome (n=5), developmental delay (n=8), autism (n=2), Treacher-Collins syndrome (n=2), and other conditions (n=8), which included cardiac disease, Crouzon's syndrome, achondroplasia, Potocki-Lupski syndrome, subglottic stenosis, skeletal dysplasia, cerebral palsy, and Pierre Robin sequence. Of these patients 58.5% (N=38) were cognitively incapable of administering PAP independently as

Table 1. Patient demographic and clinical characteristics (N=107)

Age at PAP download (years)	14.1 (2.5)
Sex (% male)	64.5
Body Mass Index (percentile)	89.0 (21.8)
Obese (% yes)	72.9
Cognitively Incapable of administering PAP independently (% Yes)	35.5
Adenotonsillectomy (% yes)	53.3
OAH1 Baseline (events/hour)	22.1 (25.9)
Oxygen Saturation during sleep (%)	96.6 (1.5)
Lowest Oxygen Saturation during sleep (%)	80.0 (12.0)
Auto-titrating Continuous PAP (N, %)	12, 11.2
Bi-level PAP (N, %)	21, 19.6
Continuous PAP (N, %)	74, 69.2
Residual AHI	2.8 (3.5)
Number of continuous days PAP adherence measured	35.4 (11.6)
Time since PAP prescribed (years)	2.2 (2.3)

All values reported as mean and (standard deviation) unless otherwise specified.

AHI Apnea hypopnea index; NS Not significant; OAH1 Obstructive apnea hypopnea index; PAP Positive airway pressure.

Table 2. Patient demographic and clinical characteristics in PAP users with and without caregiver support

	PAP users with caregiver support (N=65)	PAP users without caregiver support (N=42)	P value
Age at PAP download (years)	13.7(2.7)	14.8 (2.1)	0.03
Sex (% male)	60.0	71.4	NS
Body Mass Index (percentile)	88.1 (21.4)	90.5 (22.5)	NS
Obese (% yes)	67.7	80.9	NS
Cognitively Incapable of administering PAP independently (% Yes)	58.5	0.0	<0.01
Adenotonsillectomy (% yes)	53.3	46.7	0.03
OAHI Baseline (events/hour)	20.1 (24.9)	25.3 (27.3)	NS
Oxygen Saturation during sleep (%)	96.7 (1.5)	96.7 (1.3)	NS
Lowest Oxygen Saturation during sleep (%)	81.0 (11.3)	78.2 (12.8)	NS
Auto-titrating Continuous PAP (N)	7	5	NS*
Bi-level PAP (N)	15	6	NS*
Continuous PAP (N)	43	31	NS*
Residual AHI	3.1 (3.6)	2.4 (3.2)	NS
Number of continuous days PAP adherence measured	35.6 (12.5)	33.5 (9.9)	NS
Time since PAP initially prescribed (years)	2.6 (2.5)	1.6 (1.7)	0.02
PAP Usage			
PAP Usage per night (minutes)	298.5 (206.7)	211.9(187.2)	0.03
PAP Usage >4 hours/night (% of all nights)	55.7 (37.4)	37.6 (36.2)	0.02

All values reported as mean and (standard deviation) unless otherwise specified.

AHI Apnea hypopnea index; NS Not significant; OAHI Obstructive apnea hypopnea index; PAP Positive airway pressure.

*Distribution of PAP mode type between groups not significantly different.

confirmed by the clinical team. In the PAP users without caregiver support group (n=42), adolescents had coexisting obesity (n=35), sickle cell disease (n=2), and other conditions (n=5), which included kidney disease, cystic hygroma, Crouzon's syndrome, Treacher-Collins syndrome, and achondroplasia.

Adolescents with OSA receiving practical caregiver support with PAP used therapy for a significantly greater duration each night compared to adolescents who were not receiving practical caregiver support (298.5 [206.7] versus 211.9 [187.2]; P=0.02). See Table 2 for detailed PAP usage rates.

Results from the multiple linear regression models are shown in Table 3. After controlling for PAP mode, age, sex, the presence of obesity, having an adenotonsillectomy, time since PAP prescribed (years) and cognitive capability of administering PAP independently, caregiver support was not independently associated with PAP adherence. However, time since PAP was initially prescribed was independently associated with PAP adherence. This suggests that each year since the patient's initial PAP prescription, PAP usage increases by 32.5 minutes/night. PAP mode was also included in the regression analysis because subgroup analysis showed that PAP adherence was higher in the BPAP group compared to the CPAP group; however, this finding should be interpreted with caution as the sample size of the different PAP groups were not evenly distributed.

DISCUSSION

This study evaluated and compared adherence rates among adolescents with OSA who were using PAP therapy with and without caregiver support. Importantly, this study showed that PAP adherence rates are suboptimal among adolescents with OSA. This study showed that a longer duration since the initial PAP prescription, is independently associated with greater PAP adherence. Further, higher PAP adherence was observed in those adolescents who had support from their caregivers.

This study shows that adolescents with OSA who receive practical caregiver support with PAP have greater adherence to therapy. Practical support with medical treatment (e.g., physically administering a treatment regimen) is more beneficial for treatment adherence than emotional support (e.g., a reminder to take medication) across other conditions (23). A meta-analysis examining the effects of social support on adherence, shows treatment adherence is 1.4 times higher when patients are receiving emotional support with therapy, but 3.6 times higher when patients are receiving practical support (23). The positive impact of caregiver support on adherence has also been shown in youth with obesity or neuromuscular conditions that require bilevel noninvasive ventilation for nocturnal hypoventilation (30). In a qualitative study, Ennis et al. reported that adherent patients received practical support with therapy

Table 3. Multiple linear regression models

Covariate	β coefficients	SE	P value	95% CI	
Dependent Variable: PAP Usage per night (minutes)^b					
PAP mode	53.7	28.5	0.06	-2.8	110.2
Age	-9.9	8.0	0.22	-25.7	6.0
Sex	54.1	40.1	0.18	-25.5	133.8
Obesity	30.5	44.2	0.49	-57.3	118.3
Adenotonsillectomy	-3.0	39.1	0.94	-80.7	74.6
Time since PAP prescribed (years)	32.5	9.3	<0.01	14.1	50.9
Cognitively incapable of administering PAP independently ^a	38.4	50.4	0.45	-61.7	138.5
Caregiver Support ^a	21.9	50.3	0.66	-77.9	121.6
Dependent Variable: PAP Usage >4 hours/night (% of all nights)^b					
PAP Mode	11.6	5.4	0.03	0.9	22.3
Age	-1.5	1.5	0.33	-4.5	1.5
Sex	5.5	7.6	0.47	-9.5	20.6
Obesity	6.1	8.4	0.47	-10.5	22.8
Adenotonsillectomy	0.3	7.4	0.96	-14.4	15.0
Time since PAP prescribed (years)	4.7	1.8	0.01	1.2	8.2
Cognitively incapable of administering PAP independently ^a	6.4	9.6	0.50	-12.5	25.4
Caregiver Support ^a	8.7	9.5	0.36	-10.2	27.6

CI Confidence interval; PAP Positive airway pressure; SE Standard error.

P values were derived from linear regression adjusted for PAP Mode (automatic, bi-level, continuous), age (years), sex (male or female), presence of obesity (yes or no), adenotonsillectomy (yes or no), and the duration of PAP prescription (years).

^aCoded 0 = No 1 = Yes.

^bContinuous variables.

(e.g., help cleaning the machine, caregivers applying the mask at night) (30).

However, after controlling for time since initial PAP prescription, caregiver support was no longer a significant predictor of PAP adherence in this cohort. This may be because adolescents with OSA who have had their PAP prescription for longer have formed a habit of integrating PAP into their nightly routine and may be less reliant on caregiver support to adhere to therapy. Forming this habit early on may help patients adapt to PAP more easily, as an unpleasant initial exposure to PAP can lead to a prolonged period of treatment rejection from both the adolescent and their caregivers (31). Findings from a recent qualitative study show that adolescents with OSA find the adjustment period to PAP therapy at the beginning to be the most challenging and may benefit from having more caregiver support at this time (20).

Findings from this study suggest clinical teams should evaluate family dynamics and encourage caregivers to support their child with PAP therapy. This discussion should be facilitated when PAP is initiated, to help adolescents adapt to PAP early on, which is essential for long-term adherence (20). A recent qualitative study shows adolescents with OSA desire support with PAP therapy; however, few actually communicate this to their caregivers (20). Clinical teams play an important role in bridging the communication gap between caregivers and adolescents by stimulating discussion on who will be

responsible for administering PAP, and what level of support is desired. Further qualitative research exploring the interaction that occurs when parents apply PAP therapy to their child (e.g., effective strategies and common challenges) may improve knowledge and understanding of ways to promote PAP adherence in adolescents with OSA by clinical teams.

Suboptimal PAP adherence rates in this cohort of adolescents with OSA are similar to other studies assessing PAP adherence in children and adolescents (17,18,32). Suboptimal treatment adherence is a common concern among adolescents across a variety of chronic conditions (24). Adolescence is a unique developmental time period characterized by significant hormonal, neurological, behavioural, and psychosocial changes as youth transition into adulthood (33,34). Adolescents may find it challenging to incorporate a complex treatment regimen into their nighttime routine during this already challenging developmental period (24). During adolescence, youth also move from complete dependence on their caregivers to a more autonomous lifestyle (35). Adolescents are expected to take on greater personal responsibility for their own health care needs, but may not be ready to do so (24). Assuming an adolescent with OSA can manage PAP independently may be misleading (15) and may negatively impact adherence rates. Clinical teams should play an advocacy role by encouraging families to support their child with PAP therapy during adolescence, to improve

adherence prior to transition to adult care when parental and health care support is further limited (36). Additionally, the average PAP usage time in this cohort was 264.5 ± 202.9 minutes per night, which is less than 5 hours a night. This is not consistent with the amount of sleep needed for adolescents, a population suffering from a sleep deprivation epidemic (37). Further research on promoting longer sleep duration and longer PAP usage is needed in adolescents. Limitations of this study include the retrospective design and clinical heterogeneity of the sample, which is difficult to overcome as the majority of adolescents that require PAP for OSA are obese and/or medically complex with coexisting comorbidities. We did not have data on sociodemographic factors (e.g., race, parental education level) as it is not recorded in the patient's medical record at our institution. Finally, we did not assess emotional support for PAP use in this study (e.g., reminding a child to use PAP) as this is not documented in the child's medical record. Strengths of this study include the relatively large sample size, with a focus on adolescents.

In summary, PAP adherence is higher among adolescents with OSA who receive practical caregiver support with therapy. Further, increased duration of PAP prescription was an independent factor for PAP usage. Clinical teams should fully engage both caregivers and adolescents with OSA when initiating PAP therapy to potentially help improve adherence rates. Recognizing and addressing barriers to PAP usage in individual families can help when setting realistic and attainable goals for adherence early on, and lead to improved health outcomes in the adolescent OSA population.

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