Role of a Respiratory Therapist in Improving Adherence to Positive Airway Pressure Treatment in a Pediatric Sleep Apnea Clinic

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BACKGROUND: Many pediatric patients need positive airway pressure (PAP) for treatment of obstructive sleep-disordered breathing. Adherence to PAP (defined as percent of nights with PAP use of > 4 h) is often poor and not sustained long-term. With any chronic disease, education has been shown to help with patient outcomes. Education of patients and parents regarding PAP can be provided by different healthcare professionals. There is no published literature assessing the role of respiratory therapists (RTs) in improving adherence to PAP in children. We hypothesized that the addition of RT visits to a PAP clinic would improve PAP adherence. METHODS: RT services for PAP patients were introduced in a multidisciplinary pediatric sleep clinic in May 2006. We identified children who had been followed in clinic, and had adherence download information before and after introduction of RT services. We collected demographic, polysomnography, and CPAP adherence data at clinic visits. RESULTS: Forty-six subjects met criteria for inclusion. The mean ± SD age was 14.9 ± 6 y. The mean ± SD apnea-hypopnea index was 26.7 ± 30 events/h. Other than the addition of the RT intervention, all subjects continued to receive the same clinical services as before. Subjects were divided into 3 groups, based on baseline adherence: 0% use, use for 1–50% of nights, and use for > 50% of nights. There was a statistically significant improvement in PAP adherence in the subjects with baseline use of 0% and 1–50%, but no improvement in those with > 50% use at baseline. There was no significant change in PAP use at subsequent RT visits. CONCLUSIONS: Utilization at clinic visits of an RT trained in the use of PAP improved adherence in pediatric subjects with obstructive sleep-disordered breathing when their baseline PAP adherence was < 50%.
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Introduction

Obstructive sleep apnea, also termed obstructive sleep-disordered breathing (OSDB), is characterized by upper-airway obstruction during sleep, which causes sleep fragmentation, with or without inadequate ventilation and/or oxygenation. OSDB has been shown to be associated with significant adverse outcomes in children and adolescents, including poor school performance, hyperactivity, conduct disorder, cognitive dysfunction, quality-of-life impairment, depressive symptoms, excessive daytime sleepiness, and impaired growth.[1-3] Sleep-related breathing abnormalities have also been associated with 24-hour blood pressure dysregulation.[4] Between 2% and 11% of children are thought to have OSDB, depending on the definition used.[5,6]

OSDB in the pediatric population is primarily treated with surgery (adenotonsillectomy). However, a large number of children and adolescents continue to have OSDB following surgery or are high-risk candidates for surgery. These patients require treatment with positive airway pressure (PAP), either continuous (CPAP) or bi-level, which

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The authors have disclosed no conflicts of interest.

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has been shown to reduce the number and severity of respiratory events, and improve sleep quality, as well as the quality of life in children with OSDB.[7]

Treatment of OSDB with PAP, especially in the pediatric patients, is complicated initially by difficulties in adjusting to the PAP mask and air pressure, and later by poor long-term adherence. Studies of adults have shown poor short-term and long-term adherence to PAP.[8-10] Evidence is limited regarding pediatric adherence to PAP or successful interventions that improve pediatric adherence. Adherence to PAP in children has been reported to vary, depending on the population studied, definitions used, and the technique used for measuring adherence. For example, a study of PAP use in children 6 months after initiation showed a high dropout rate (28%) and suboptimal use of PAP in those who continued to use it.[11]

In patients with any chronic illness, education improves outcomes.[12-15] Education of patients and caregivers regarding the medical necessity of PAP, how to use and clean the equipment, and addressing barriers causing poor adherence improves adherence to PAP treatment in adults with OSDB.[15] Healthcare professionals, including physicians, nurses, respiratory therapists (RTs), and psychologists, can provide PAP education for pediatric patients and their families. In an effort to provide better care for our patients and to improve PAP adherence, a designated RT skilled in the use of PAP in children and adolescents joined the multidisciplinary Pediatric Sleep Disorders Clinic held at our tertiary care children's hospital. As there is no published literature assessing the role of RTs in improving long-term adherence to PAP in the pediatric population, we sought to evaluate the effect of regular education and intervention, provided by an RT, on adherence to PAP therapy in our center. We hypothesized that the addition of an RT intervention to the regular clinic visit would improve PAP adherence in children and adolescents with OSDB.

QUICK LOOK

Current knowledge

Many pediatric patients need positive airway pressure (PAP) for treatment of obstructive sleep disordered breathing. Patient adherence to PAP equipment is poor and not sustained long-term. Education of patients and parents regarding PAP use can improve adherence.

What this paper contributes to our knowledge

Utilization of a respiratory therapist trained in the use of PAP in children and adolescents significantly improved adherence to PAP in pediatric patients with obstructive sleep disordered breathing and poor baseline adherence.

Methods

This study was approved by the institutional review board of the University of Arkansas for Medical Sciences (study 109357). This was a retrospective medical records review study in a large pediatric sleep disorders center located in a free-standing, tertiary care children's hospital with a multidisciplinary sleep disorders clinic that is held 3 days per week and is staffed by 2 neurologists, 3 pulmonologists, an otolaryngologist, specialty nurses, psychologists, and an RT who is also a registered polysomnographic technologist. Until May 2006, the sleep disorders clinic functioned without an RT to provide PAP equipment evaluation, education, and follow-up for children initiated on PAP therapy.

In an effort to provide better care and to improve PAP adherence, a designated RT skilled in the use of PAP in children joined the multidisciplinary team in May 2006. In general, subjects on PAP with good adherence were seen at an average interval of 6–12 months, and those with poor adherence were seen every 3 months, depending on the underlying problem. This frequency of clinic visits did not change with the addition of the RT services; the RT equipment evaluation and educational services were added to the regular visit. All patients seen in the multidisciplinary sleep disorders clinic were instructed to bring their PAP machine to the clinic visit following the introduction of the RT service in clinic.

The RT's role in the Sleep Disorders Clinic includes, but is not limited to, the following: evaluating the PAP machine, including masks and tubing; verifying correct PAP settings; educating patients and families regarding PAP and the importance of wearing PAP; cleaning and disinfecting the equipment; evaluating for correct mask fit and/or providing alternative masks with better fit; advocating for patient needs with durable medical equipment companies; downloading PAP adherence information; explaining the utility of key features of the machine (alarm, ramp setting, humidification); suggesting evaluation by physician for potential benefit from a topical nasal decongestant/steroid use when needed; and reviewing previous polysomnogram test results with patients to remind them about the need for treatment. Education provided by the RT is in addition to the usual patient and caregiver education by the other care providers.

Study Subjects

Patients who were treated with PAP and were followed in the sleep disorders clinic between June 2006 and December 2008 were included in the study. All subjects who had been prescribed PAP at least 1 month before their first visit with the RT and had PAP adherence information available at the first RT visit were included in the study. PAP adherence information before and after introduction of the RT was extracted. Demographics, comorbidities, and polysomnography data were recorded.

Assessment of PAP Adherence

PAP adherence was defined as the percentage of nights that PAP was used for > 4 hours. Based on current Medicare guidelines, adequate PAP adherence is defined > 4 h/night PAP use for > 70% of nights. PAP adherence was objectively assessed based on smart card downloads. A smart card is a pocket-sized plastic card with an embedded integrated circuit that stores data on times of use, machine on and off times, and hours of use/24 hours. The software provides numerical data and graphical plots of adherence information. This information during the first visit with the RT was used as the baseline data representing the pre-intervention information. The differences between the adherence rates at subsequent visits and the first visit were defined as changes in adherence.

Psychology Evaluation

A subgroup of subjects with poor PAP adherence, comorbid mood and/or behavioral problems, important family stressors, and/or family dynamics that could impact adherence were also seen by a psychologist before, on the same day, or after the first RT visit. The referral to a psychologist was based on the physician's subjective assessment, without standardized criteria. The encounter with the psychologist included an initial detailed psychological assessment of strengths and barriers to adherence, and the provision of a variety of behavioral strategies to the treatment plan to promote adherence.[16]

Statistical Analysis

All the analyses were performed using statistics software (R 2.15.0, R Foundation, Vienna, Austria, and SAS 9.3, SAS Institute, Cary, North Carolina). Because all the subjects had the RT intervention at the first (baseline) visit, the baseline adherence rates were considered the pre-RT adherence rates, while the adherence rates measured at the second, third, and fourth visits were considered as post-RT adherence rates. Subjects were divided into 3 subgroups: baseline adherence rate 0%, baseline adherence rate 1–50%; and baseline adherence rate 50–100%.

Descriptive statistics are expressed as mean ± SD and median (IQR) for continuous variables, and frequency and percentage for categorical variables. The improvement in adherence rate at the second, third, and fourth visit was calculated by subtracting the baseline adherence rate from the adherence rate at the second, third, or fourth visit. Under the assumption that the improvement in adherence rate was approximately normally distributed, longitudinal analysis was conducted for the improvement in adherence rate using a mixed model to assess the repeated measured improvements as a function of baseline group (0% at baseline, 1–50% at baseline, and 50–100% at baseline), visit (second, third, and fourth visit), and the interaction between the 2 after adjusting for the covariates, including the time from baseline visit to the following visit, the psychology intervention, and the duration that the subject was exposed to PAP prior to the intervention. This model was designed to test the adherence improvement at the second, third, and fourth visit for each baseline subgroup after adjustment for the time between visits, the psychology intervention, and the duration of PAP use prior to the RT intervention. An autoregressive covariance matrix was specified when fitting the model. $P < .05$ was considered to indicate statistical significance.

Results

A total of 46 subjects using PAP for OSDB were seen by the multidisciplinary clinic over the 30-month study period. Twelve (26%) had a baseline adherence rate of 0%; 12 (26%) had a baseline adherence rate of 1–50%; and 22 (48%) had a baseline adherence rate > 50% (Table 1). Comorbidities included Down syndrome (8 subjects), Prader-Willi syndrome (1), King-Denborough syndrome (1), fetal alcohol syndrome (1), Treacher-Collins syndrome (1), achondroplasia (1), and velopharyngeal insufficiency (1). There were 2 (4%) missing values for each of body mass index, apnea-hypopnea index, and duration of PAP use prior to the initial visit. Twenty-five (53%) subjects had at least one psychologist visit before the 4th visit (11 in the 0% baseline adherence subgroup, 9 in the 1–50% subgroup, and 5 in the 50–100% subgroup). Among these 25 subjects, 5 (20%) had their first psychologist visit before the first RT visit; 14 (70%) had their first psychologist visit before the second RT visit; 4 had their first psychologist visit before the third RT visit; and 2 had their first psychologist visit before the fourth RT visit.

Effects of the RT Intervention on PAP Adherence

The objective adherence rate was available for all subjects at the first 2 visits (baseline and second visit). However, the adherence information was missing for 1 (2%) and 8 (17%) subjects at the third and fourth visits, respectively. Therefore, there were a total of 175 longitudinal measurements. The adherence rate at each visit within each baseline adherence subgroup is summarized in Table 2. The box plots of the adherence rates are shown in Figure 1, and the mean adherence rate for each visit within each baseline adherence category is shown in Figure 2.

The mixed model was fitted to the improvement in adherence rate to evaluate the improvement in adherence rate after RT intervention, and the results of the model are shown in Table 3. For the subgroup with 0% baseline adherence, significant improvement was found at the second visit, compared to the baseline: estimated improvement 24%, 95% CI 6–43%, $P = .01$). However, we did not detect sig-

Table 1. Baseline Characteristics of Subjects in Each Subgroup

	All Subjects $n = 46$	Baseline Adherence Rate Category			P*
		0% $n = 12$	1–50% $n = 12$	50–100% $n = 22$	
Age					.53
Mean ± SD	14.9 ± 6.0	16.0 ± 3.8	14.6 ± 8.6	14.5 ± 5.4	
Median (IQR)	15.5 (12.0–18.0)	17.0 (15.5–18.0)	13.0 (11.5–15.2)	15.5 (11.2–18.0)	
Body mass index					.01
Mean ± SD	36.7 ± 13.2	45.6 ± 12.8	34.4 ± 11.9	32.8 ± 12.2	
Median (IQR)	35.5 (28.3–43.5)	44.8 (38.1–57.0)	33.4 (28.6–40.2)	33.6 (20.9–36.6)	
Missing, no. (%)	2 (4)	0 (0)	0 (0)	2 (9)	
Apnea-hypopnea index†					.72
Mean ± SD	26.7 ± 30.0	33.1 ± 37.7	20.1 ± 16.7	27.2 ± 32.1	
Median (IQR)	16.1 (8.4–35.5)	15.1 (10.1–36.2)	15.9 (8.4–25.3)	17.1 (5.7–34.8)	
Missing, no. (%)	2 (4)	1 (8)	0 (0)	1 (5)	
Prior PAP use, d					.92
Mean ± SD	515.7 ± 592.4	522.8 ± 411.7	471.9 ± 335.1	537.8 ± 793.4	
Median (IQR)	329.0 (103.0–684.8)	432.0 (233.5–699.5)	329.0 (275.8–700.0)	174.5 (90.0–674.0)	
Missing, no. (%)	2 (4)	0 (0)	0 (0)	2 (9)	
Male, no. (%)	29 (63)	9 (75)	7 (58)	13 (59)	.73
Race, no. (%)					.16
White	19 (41)	4 (34)	3 (25)	12 (55)	
African American	24 (52)	7 (58)	9 (75)	8 (36)	
Other	3 (7)	1 (8)	0 (0)	2 (9)	
Psychology intervention,‡ no. (%)	25 (54)	11 (92)	9 (75)	5 (23)	< .001

* P values are from comparisons of 3 groups, using analysis of variance for continuous variables, and the Fisher exact test for categorical variables.
† One subject had an apnea-hypopnea index of 0 events/h but had snoring and CO_2 retention and was started on bi-level positive airway pressure.
‡ Psychology intervention happened before the 4th visit.
PAP = positive airway pressure

Table 2. Summary of the Adherence Rate at Each Visit Within Each Baseline Adherence Subgroup

	Baseline Adherence Rate Category		
	0% $n = 12$	1–50% $n = 12$	50–100% $n = 22$
Baseline adherence rate			
Mean ± SD	0 ± 0	0.30 ± 0.13	0.78 ± 0.14
Median (IQR)	0 (0–0)	0.32 (0.23–0.38)	0.81 (0.69–0.88)
2nd visit adherence rate			
Mean ± SD	0.26 ± 0.30	0.52 ± 0.35	0.79 ± 0.20
Median (IQR)	0.20 (0.00–0.35)	0.60 (0.26–0.77)	0.87 (0.67–0.95)
3rd visit adherence rate			
Mean ± SD	0.32 ± 0.32	0.50 ± 0.32	0.73 ± 0.25
Median (IQR)	0.23 (0.09–0.49)	0.49 (0.32–0.71)	0.81 (0.58–0.91)
Missing, no. (%)	1 (8)	0 (0)	0 (0)
4th visit adherence rate			
Mean ± SD	0.49 ± 0.39	0.58 ± 0.35	0.78 ± 0.22
Median (IQR)	0.60 (0.12–0.84)	0.70 (0.49–0.82)	0.86 (0.17–0.92)
Missing, no. (%)	1 (8)	3 (25)	4 (18)

nificant further improvement at subsequent RT visits. ($P = .31$ and 0.10). In the group with baseline usage of 0% nights for > 4 h/night, one out of 12 subjects improved to > 70% usage at the second visit, 2 out of 12 subjects improved to > 70% usage at the third visit, and 4 out of 12 subjects improved to > 70% usage at the fourth visit.

Similar results were observed for the subgroup with 1–50% baseline adherence. There was significant improve-

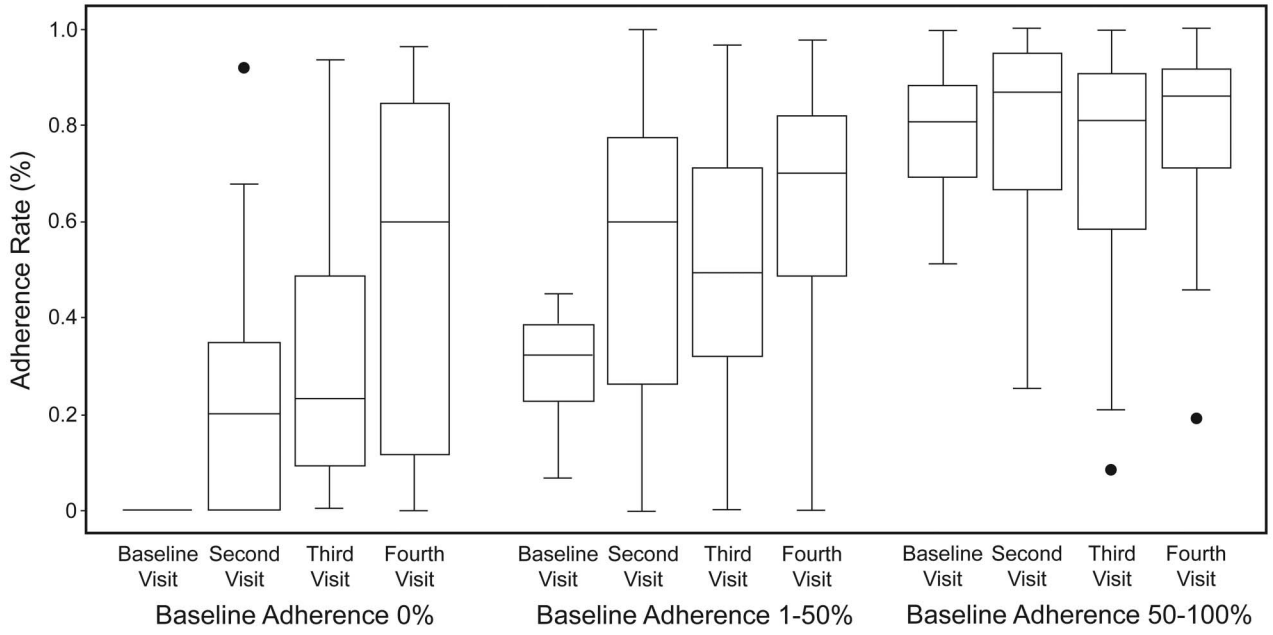

Fig. 1. Adherence rate by visit.

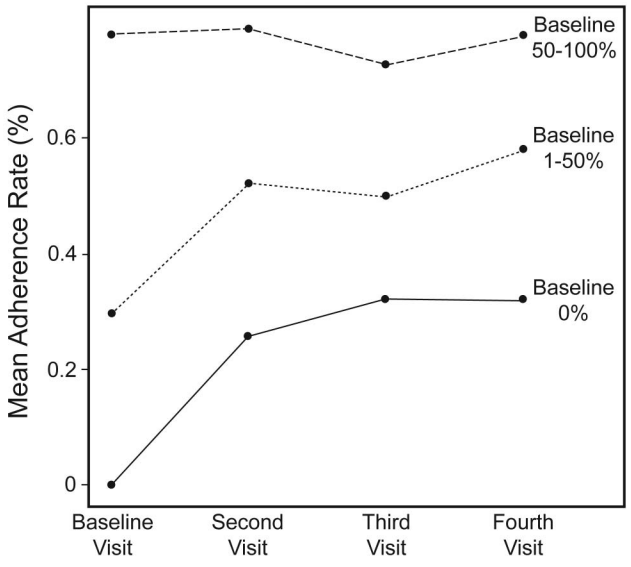

Fig. 2. Mean adherence rate by visit.

ment in adherence rate at the second visit, compared to the baseline: estimated improvement 22%, 95% CI 2–41%, $P = .03$. No significant improvements were made afterwards ($P = .90$ and .39). Four of 12 subjects improved to $> 70\%$ at the second visit. Four of 12 subjects improved to $> 70\%$ at the third visit. Five of 12 subjects improved to $> 70\%$ at the fourth visit.

For the subgroup with 50–100% baseline adherence, we did not see any significant improvement, as expected ($P = .96$, .44, and .27). There was no significant effect of psychology intervention ($P = .81$). The subjects had been on PAP therapy for a variable period of time (3–20 months) prior to RT intervention, and neither the duration that the subject was exposed to PAP prior to the intervention nor the time between the visits was found to significantly affect the improvement in adherence rate ($P = .45$ and .77). Five of the 6 subjects in this group who had $< 70\%$ adherence at the first visit improved to $> 70\%$ adherence by their last visit during the study period.

Discussion

This small, observational, retrospective study found that the RT intervention improved PAP adherence in the subjects who had very poor adherence, but did not improve adherence in the group who used their PAP for $> 50\%$ of the nights before the intervention. Our results also suggest that most of the advantage of the RT intervention occurred at the first visit. The subsequent RT visits might help maintain the improved adherence, which would be an advantage, since adherence is known to decrease over time.[11] Further research with a control group (ie, with only one RT visit) is necessary to support that speculation.

What constitutes a clinically important improvement in PAP adherence is yet to be defined. Most of our subjects improved in the percentage of nights they used PAP for ≥ 4 h/night. About one third of the subjects improved to the accepted standard of $> 70\%$ use for > 4 h/night.

Previous studies have found improved PAP adherence from interventions such as mask optimization, PAP edu-

Table 3. Summary of the Results Based on the Mixed Model

	Baseline Adherence Rate Category		
	0% *n* = 12	1–50% *n* = 12	50–100% *n* = 22
Improvement in Adherence Rate*			
2nd vs baseline visit			
Estimate (95% CI)	0.24 (0.06–0.43)	0.22 (0.02–0.41)	−0.004 (−0.17 to 0.16)
P	.01	.03	.96
3rd vs 2nd visit			
Estimate (95% CI)	0.10 (−0.09 to 0.29)	−0.01 (−0.20 to 0.18)	−0.06 (−0.22 to 0.10)
P	.31	.90	.44
4th vs 3rd visit			
Estimate (95% CI)	0.17 (−0.04 to 0.37)	0.08 (−0.11 to 0.27)	0.09 (−0.07 to 0.25)
P	.10	.39	.27

* The estimated improvements were obtained after adjusted for the time between visits, the psychology intervention, and the duration of positive airway pressure use prior to the intervention.

cation, heated humidification, and nasal steroids.[15] Education about OSDB and PAP improved adherence in adults, including in subjects who had prior prolonged experience with PAP.[17-19] In children there have been few studies of PAP adherence. Behavioral interventions, including parent education and graded mask introduction, improve PAP adherence.[20-22] We hypothesize that in our subjects the positive effect of the RT visits was due to combined effects of education, mask optimization, coordination of equipment requirements with the durable medical equipment company, positive reinforcement, equipment check, and close follow-up. The relative contribution of each of these components could not be determined in this retrospective study.

Good adherence during the initial period of PAP introduction predicts persistent good adherence.[23] This was observed in the present study as well. About half of our subjects had > 50% adherence before the intervention, and maintained that adherence rate throughout the study (albeit with RT intervention). It may be argued that RT intervention improved adherence only in the subjects with low baseline adherence because the group with adherence > 50% already had "good" adherence and could not improve more. Although the median adherence rate in this group was 0.81%, the range extended to 0.51 (see Table 2). Thus, although the presence of the RT did not enhance adherence in this group, further improvement in PAP adherence would have been possible for most of the subjects with high baseline adherence.

Another potentially clinically relevant finding was that the duration for which the subject had the PAP equipment at home (in other words, the delay in the RT intervention relative to PAP initiation) did not affect the improvement in the adherence. Thus, the duration of PAP therapy does not appear to affect the efficacy of the future RT intervention. Although the subjects with the poorest adherence got the most benefit from RT intervention, their adherence rate never reached that of the subjects with better baseline adherence, indicating that in a subset of subjects it may be difficult to achieve ideal adherence. We also do not know if earlier intervention (ie, introduction of adherence improvement programs before introduction to PAP equipment) will help in achieving higher adherence in these individuals.

Our study did not demonstrate a statistically significant advantage of intervention by a psychologist as part of a PAP adherence program in children and adolescents. This may be because the majority of the subjects in the group receiving psychologist intervention had one or more comorbidities and/or lower adherence to start with. Since this study was completed there has been a change in practice at the clinic; the psychologists on the team see all patients who are prescribed PAP (not just the select few with noticeable comorbidities), to provide an intensive desensitization and reinforcement behavioral program.[16] Also, the number of subjects in the study was too small to conduct subgroup analysis to determine the added advantage of the psychologist intervention. Additional intervention by a psychologist may be advantageous, but a larger study with controls will be required to test that hypothesis.

There was a statistically significant difference in body mass index between the 3 subgroups. The importance of this finding is not clear. Due to small sample size, we could not study the effect of body mass index on the response of adherence to the RT intervention. Further study with a larger study population may be able to research this effect.

There are several limitations to our work. This was a retrospective study, so not all information was available for all subjects. We did not have data on personality characteristics of the subjects and/or caregivers, which may affect response to intervention. The small sample size may have led to negative results in some cases; for instance, although we saw gradual improvement in adherence over subsequent visits in many subjects, this was not statisti-

cally significant. Also, the improvement in adherence in subjects with good baseline adherence was not statistically significant. We also did not have a control group of subjects without RT intervention during the same time period. However, we included only those subjects who had been using PAP before RT introduction in the clinic; hence, the subjects served as their own controls. An additional potential confounding factor was that some subjects received psychology intervention while others did not. The effect of the psychology intervention was not statistically significant in improving the adherence rate. However, the selection of subjects with lower baseline adherence may have masked an effect of the psychology intervention. This was a small, retrospective, exploratory study. A larger, prospective study is necessary to determine the impact of RT or psychology intervention and support on PAP adherence in children with OSDB.

Conclusions

Utilization at clinic visits of an RT trained in the use of PAP in children and adolescents significantly improved adherence to PAP in pediatric subjects with OSDB and with poor baseline adherence, and in some subjects improved it up to the standard for adherence. Similarly, routine follow-up visits by an RT in the clinic may help to maintain improved adherence in subjects with poor initial adherence, although this needs to be proven using a control group.

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