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Role of a Respiratory Therapist in improving adherence with positive airway pressure treatment in a Pediatric Sleep Apnea Clinic

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Abstract

Background: Many pediatric patients need positive airway pressure (PAP) for treatment of obstructive sleep disordered breathing (OSDB). Adherence with use of PAP equipment (defined as percent of nights with nightly use of PAP for more than 4 hours) 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 use can be provided by different health care professionals. There is no published literature assessing role of respiratory therapists in improving adherence with PAP in children. We hypothesize that addition of respiratory therapist (RT) visits to a PAP clinic helps in improving 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 information regarding demographic data, polysomnogram data, and CPAP adherence at clinic visits.

Results: Forty six patients met criteria for inclusion. The mean age was 14.6 years (SD 6). The mean apnea hypopnea index was 26.7/hr (SD 30). Other than addition of RT intervention, all patients continued to receive the same clinical services as before. Patients were divided into 3 groups based on baseline adherence: 0% use, use for 1-50% nights, use for >50% nights. There was a statistically significant improvement in use of PAP in patients 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.

Conclusion: Utilization at clinic visits of a respiratory therapist trained in the use of PAP improves adherence in pediatric patients with OSDB when their baseline PAP adherence rate is less than 50%.

Keywords: Continuous Positive Airway Pressure, Patient adherence, pediatrics, respiratory therapy department, obstructive sleep apnea, education of patients

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INTRODUCTION

Obstructive sleep apnea (OSA), also termed obstructive sleep disordered breathing (OSDB) is characterized by upper airway obstruction during sleep that 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-h blood pressure dysregulation. Between 2 to 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 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]

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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 with use of PAP.[8-10] Evidence is limited regarding pediatric adherence with PAP treatment or successful interventions that improve pediatric adherence. Adherence with 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 six 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 for PAP treatment, how to use and clean the equipment, and addressing barriers causing poor adherence improves adherence to PAP treatment in adults with OSDB.[15] Health care professionals including physicians, nurses, respiratory therapists, 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 respiratory therapist (RT) skilled in the use of PAP in children and adolescents joined the multidisciplinary Pediatric Sleep Disorders Clinic held at a tertiary care children's hospital. As there is no published literature assessing the role of respiratory therapists in improving long-term adherence with PAP utilization in the pediatric population, we sought to evaluate the effect of regular education and intervention, provided by an RT, on adherence with PAP therapy in our center. We hypothesized that the addition of RT intervention to the regular clinic visit

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improves PAP adherence in children and adolescents with OSDB.

METHODS

Design: Retrospective medical records review. **Setting:** 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 three days per week and is staffed by 2 neurologists, 3 pulmonologists, an otolaryngologist, specialty nurses, psychologists, and a respiratory therapist who is also a registered polysomnographic technologist. Until May 2006, the sleep disorders clinic functioned without a respiratory therapist 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 respiratory therapist skilled in the use of PAP in children joined the multidisciplinary team in May 2006. In general, patients on PAP with good adherence were seen at an average interval of 6 to 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 was added to the regular visit. All patients seen in the multidisciplinary sleep disorders clinic are instructed to bring their PAP machine to the clinic visit since introduction of the RT service in clinic.

The Respiratory Therapist's role in the Sleep Disorders Clinic includes, but is not limited to, the following: evaluating the PAP machine including masks and tubing, verifying

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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 DME 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 the study. All patients 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) in the sleep disorder clinic was extracted. Patient demographics, co-morbidities, and PSG related information was recorded. This study was approved by the Institution Review Board at University of Arkansas Medical Sciences (IRB# 109357).

Assessment of PAP adherence: Adherence to use of PAP is defined as percentage of nights that PAP is used for more than 4 hours. Based on current Medicare guidelines, adequate PAP adherence is defined as use of PAP for more than 4 hours nightly for more than 70% of the nights. In our study, PAP adherence information was objectively

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assessed based on smart card downloads. A smart card is a pocket-sized plastic card with an embedded integrated circuit that stores data about use of the machine at the prescribed pressure. Specifically, these data include times of use, machine on and off time, hours of use/24 hours, etc. for each date during the interval since the last download. The software provides numerical data as well as graphical plots of the specific adherence information for each patient at each visit. This information during the first visit with the RT was used as "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 patients with poor PAP adherence, comorbid mood and/or behavioral problems, significant family stressors, and/or family dynamics that potentially may 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. Encounter with the psychologist included an initial detailed psychological assessment assessing 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 R version 2.15.0 (R Development Core Team, Vienna, Austria) and SAS version 9.3 (SAS Institute Inc., Cary, NC). Because all the

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patients in the study had the RT intervention at their first visits (baseline visits), the first (baseline) adherence rates were considered pre-RT adherence rates, while the adherence rates measured at the following visits (second, third, and fourth visits) were considered as post-RT adherence rates. Patients were divided into three subgroups with respect to their baseline adherence rates: the first subgroup included patients with 0% baseline adherence rate; the second subgroup consisted of patients with 1% to 50% baseline adherence rate; and the third subgroup included patients with 51% to 100% baseline adherence rate.

Descriptive statistics were expressed as mean ± standard deviation, median (interquartile range) for continuous variables, and frequency and percentage for categorical variables. We plotted the adherence rates at each visit for each subgroup using boxplot, and the mean adherence rate at each visit was also plotted for each subgroup separately.

The improvement in adherence rate at the second, third, and fourth visit was calculated by subtracting the baseline adherence rates from the adherence rates at the second, third, and fourth visit, respectively. Under the assumption that the improvement in adherence rate was approximately normally distributed, longitudinal analysis was conducted for the improvement in adherence rate using the mixed model to assess the repeated measured improvements as a function of baseline groups (0% baseline, 1-50% baseline, and 51-100% baseline), visits (second visit, third visit, and fourth visit), and the interactions between the two after adjusting for the covariates including the time from baseline visits to the following visits, the psychology intervention and the duration that the patient was exposed to PAP prior to the intervention. This model specification was designed to test for the improvement in adherence rate at the second, third, and fourth visit for each

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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-values less than 0.05 were considered to indicate statistical significance.

RESULTS

A total of 46 patients using PAP for OSDB were seen by the multidisciplinary clinic over the 30-month study period. Of these 46 patients, 12 (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 greater than 50%. The characteristics of the patients in each subgroup are summarized in **Table 1**. In addition to OSDB, other diagnoses in these patients included Down syndrome (8 patients), 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 BMI, AHI and the duration of PAP use prior to the initial visit respectively. A total of 25 (53%) patients 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 51-100% subgroup). Among these 25 patients, 5 (20%) patients had their first psychologist visit before the first RT visit; 14 (70%) patients had their first psychologist visit before the second RT visit; 4 patients had their first psychologist visit before the third RT visit; and 2 patients had their first psychologist visit before the fourth RT visit.

Effects of RT intervention on PAP adherence:

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The objective adherence rate was available for all patients at the first two visits (baseline and second visits). However, the adherence information was missing for 1 (2%) and 8 (17%) patients 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 boxplots 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 2nd visit compared to the baseline [estimated improvement 24%, 95% CI (6%, 43%), p=0.01]. However, we did not detect significant further improvement at subsequent RT visits. (p=0.31 and 0.10). In this group with baseline usage on 0% nights for more than 4 hours/ night, one out of 12 patients improved to more than 70% usage at the second visit, 2 out of 12 patients improved to more than 70% usage at the third visit, and 4 out of 12 patients improved to more than 70% usage at the fourth visit.

Similar results were observed for the subgroup with 1-50% baseline adherence. There was significant improvement in adherence rate at the second visit compared to the baseline [estimated improvement 22%, 95% CI (2%, 41%), p=0.03]. No significant improvements were made afterwards (p=0.90 and 0.39). Four (4) of 12 patients improved

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to more than 70% at the second visit. Four (4) of 12 patients improved to more than 70% at the third visit. Five (5) of 12 patients improved to more than 70% at the fourth visit. For the subgroup with 51-100% baseline adherence, we did not see any significant improvement as expected (p=0.96, 0.44, and 0.27). There was no significant effect of psychology intervention (p=0.81). The patients had been on PAP therapy for a variable period of time (3 months – 20 months) prior to RT intervention, and neither the duration that the patient was exposed to PAP prior to the intervention nor the time between the visits was found to significantly affect the improvements in adherence rate (p=0.45 and 0.77). 5 of the 6 patients in this group that had less than 70% adherence at the first visit improved to more than 70% adherence by their last visit during the study period.

DISCUSSION

This small, observational, retrospective study sought to determine whether the presence of a respiratory therapist in a PAP clinic improves adherence to PAP therapy in children and adolescents with OSDB. The results showed that intervention by a respiratory therapist in a multidisciplinary pediatric clinic is beneficial for improving adherence with PAP use in pediatric patients who have very poor adherence. However, it does not seem to improve adherence further in the group who are using their PAP for more than 50% of the nights before the intervention. The results of this study also suggest that most of the advantage of RT intervention seems to occur at the first visit. Additional visits may help to maintain the improved adherence rate (without further improvement or deterioration)

which in itself may be an advantage as reduction in adherence over time is well known.[11] Further research with a control group (i.e. with only one RT visit) is necessary to confirm this conclusion.

A clinically significant improvement in usage of PAP equipment is yet to be defined. Most patients in this study showed some improvement in percentage of nights they used the equipment for 4 hours or more/ night. About one-third of the patients showed improvement to the accepted standard of "more than 70% use for more than 4 hours per night."

Previous studies have shown advantage of interventions such as mask optimization, PAP education, heated humidification, and nasal steroids in improving adherence to PAP use.[15] Education about OSDB and PAP mechanism have been shown to improve adherence in adults using PAP for OSDB, including in patients who have had a prior prolonged period of exposure to PAP.[17-19] In children, very few studies assessing ways to improve PAP adherence are available. Behavioral intervention including parent education and graded mask introduction has been shown to improve adherence to PAP.[20-22] We hypothesize that in our group of pediatric patients, the positive effect of the RT was due to a combined advantage of education, mask optimization, co-ordination of equipment requirements with the DME company, positive reinforcement, equipment check and a close follow-up. The relative contribution of each of these components could not be determined in this retrospective study.

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It has been shown that good adherence in the initial period of PAP introduction predicts persistent good adherence.[23] This was observed in the present study as well. About half of our patients had greater than 50% adherence before the intervention, and maintained this adherence rate throughout the study (albeit with RT intervention). It may be argued that RT intervention only improved the group with low baseline adherence because the others (group with adherence rate >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 (Table 2). Thus, although presence of the RT did not enhance adherence in this group, further improvement in adherence to PAP therapy would have been possible for most of the patients with a high baseline adherence rate.

Another potentially clinically relevant finding was that the duration for which the patient 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 patients with the poorest adherence got the most benefit from RT intervention, their adherence rate never reached the level of the patients with better baseline adherence indicating that in a subset of patients it may be difficult to achieve ideal adherence rates. We also do not know if earlier intervention (i.e. introduction of adherence improvement programs before introduction to PAP equipment) will help in achieving higher adherence rates in these individuals.

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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 patients in the group receiving psychologist intervention had one or more of a variety of comorbid conditions and/or lower adherence to start with. Since this study was completed there has been a change in practice at the clinic in that psychologists on the team see all patients who are prescribed PAP treatment (not just the select few with noticeable comorbidities) to provide an intensive desensitization and reinforcement behavioral program.[16] Also, the number of patients in the study was too small to conduct subgroup analysis to determine the added advantage of the psychologist intervention. Additional intervention by psychologist may be advantageous, but a larger study with controls will be required to make this observation.

There was a statistically significant difference in BMI between the 3 groups made based on baseline adherence. The significance of this finding is not clear. Due to small sample size, we did not study the effect of BMI on the response of adherence to RT intervention. Further studies with larger study population may be able to study this effect.

There are several limitations to our study. This is a retrospective study; hence all information on all patients was not available. We do not have data on personality characteristics of the patients and/or caregivers, which may affect response to intervention. The small sample size may have led to negative results in some cases; e.g. although we saw gradual improvement in adherence over subsequent visits in many patients, this was not statistically significant. Also, the improvement in adherence in

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patients with good baseline adherence was not statistically significant. We also did not have a control group of patients without RT intervention during the same time period. However, we had included only those patients that had been using PAP before RT introduction in the clinic; hence the patients served as their own controls. An additional, potential confounding factor was that some patients 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 patients with lower baseline adherence rates may have masked an effect of psychology intervention. This study was a small, retrospective, exploratory study. Larger, prospective studies are necessary to better define the impact of RT or psychology intervention and support on PAP adherence in children with OSDB.

CONCLUSIONS

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

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FIGURE LEGENDS

Figure 1: Boxplots of adherence rates for each visit within each baseline adherence subgroup

Figure 2: Graph of mean adherence rate for each visit within each baseline adherence subgroup

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Table 1: Baseline characteristics of patients in each subgroup (SD=standard deviation, IQR=interquartile range)

	All Patients (N=46)	**0% Baseline (N=12)**	**1-50% Baseline (N=12)**	**51-100% Baseline (N=22)**	**p[a]**
Age					0.53
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)	
BMI					0.01
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 N (%)	2 (4%)	0 (0%)	0 (0%)	2 (9%)	
AHI[b]					0.72
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 N (%)	2 (4%)	1 (8%)	0 (0%)	1 (5%)	
Prior PAP use (days)					0.92
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 N (%)	2 (4%)	0 (0%)	0 (0%)	2 (9%)	
Male N (%)	29 (63%)	9 (75%)	7 (58%)	13 (59%)	0.73
Race N (%)					0.16
Caucasian	19 (41%)	4 (34%)	3 (25%)	12 (55%)	
African American	24 (52%)	7 (58%)	9 (75%)	8 (36%)	
Others	3 (7%)	1 (8%)	0 (0%)	2 (9%)	
Psychology intervention[c] N (%)	25 (54%)	11 (92%)	9 (75%)	5 (23%)	<0.001

[a] P-values were obtained based on comparisons of three groups using analysis of variance (ANOVA) for continuous variables, and the Fisher's exact test for categorical variables.
[b] There was a patient with AHI of 0/hr but with snoring and CO2 retention started on BiPAP.
[c] Psychology intervention happened before the 4th visit.

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Table 2: Summary of the adherence rate at each visit within each baseline adherence subgroup (SD=standard deviation, IQR=interquartile range)

	0% Baseline (N=12)	1-50% Baseline (N=12)	51-100% Baseline (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, N (%)	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, N (%)	1 (8%)	3 (25%)	4 (18%)

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Table 3: Summary of the results based on the mixed model

Improvement in Adherence Rate	0% Baseline (N=12)	1-50% Baseline (N=12)	51-100% Baseline (N=22)
2nd vs. Baseline Visit			
Estimate (95% CI)	**0.24 (0.06, 0.43)**	**0.22 (0.02, 0.41)**	-0.004 (-0.17, 0.16)
P-value	**0.01**	**0.03**	0.96
3rd vs. 2nd Visit			
Estimate (95% CI)	0.10 (-0.09, 0.29)	-0.01 (-0.20, 0.18)	-0.06 (-0.22, 0.10)
P-value	0.31	0.90	0.44
4th vs. 3rd Visit			
Estimate (95% CI)	0.17 (-0.04, 0.37)	0.08 (-0.11, 0.27)	0.09 (-0.07, 0.25)
P-value	0.10	0.39	0.27

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

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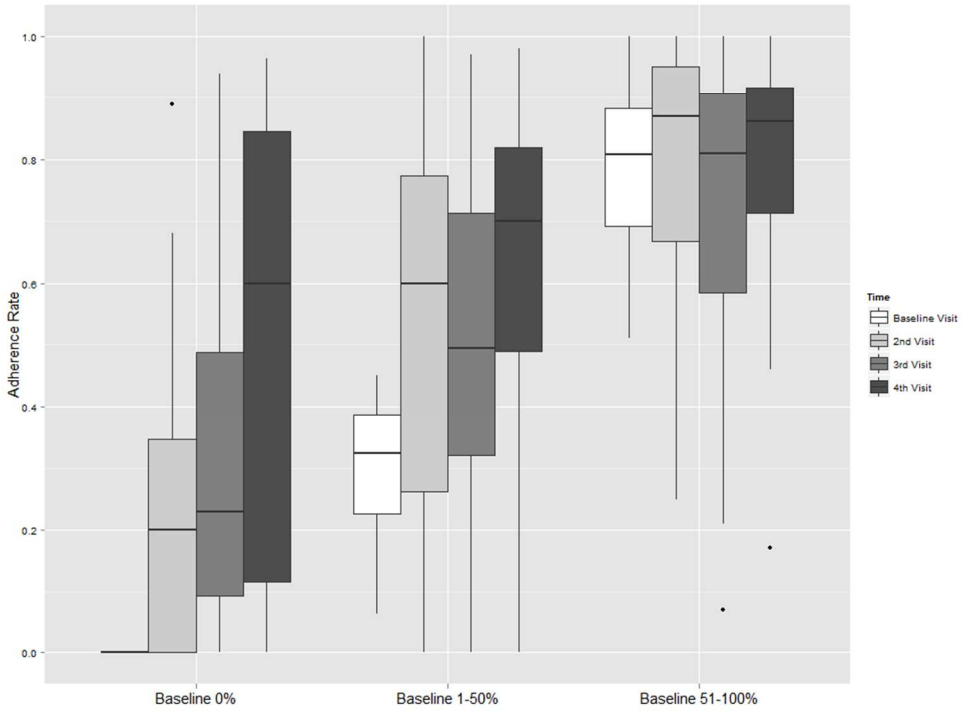

Boxplots of adherence rates for each visit within each baseline adherence subgroup
264x197mm (96 x 96 DPI)

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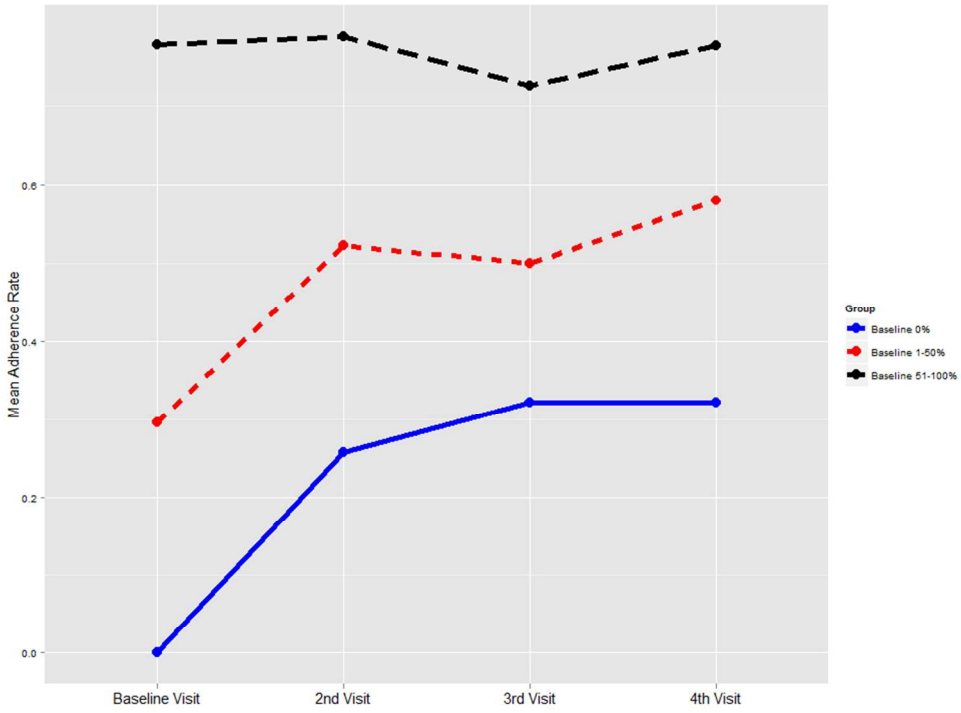

Graph of mean adherence rate for each visit within each baseline adherence subgroup
264x197mm (96 x 96 DPI)