Study Objective: The purposes of this study were (1) to describe behavior interventions provided to improve compliance with positive airway pressure (PAP) therapies in children with obstructive sleep apnea, (2) to survey physician and caregiver satisfaction with these interventions, and (3) to present preliminary outcome data on the effects of these interventions.

Design: Retrospective, descriptive analysis.

Setting: Pediatric psychology consultation service at a university-affiliated rehabilitation hospital.

Participants: 20 children (aged 1-17 years) with obstructive sleep apnea, referred by physicians for noncompliance with PAP.

Interventions: Patients self-selected into 1 of 3 groups: (1) a group receiving a 1.5-hour consultation and recommendation session (CR+), (2) a group receiving consultation and recommendations plus a course of behavior therapy (BT), and (3) a group for whom behavior therapy was recommended after the consultation and recommendations, but the family did not follow-up (CR-).

Results: Prior to behavior intervention, none of the children were consistently wearing the PAP equipment. After intervention, 75% of children who received behavior intervention (CR+ and BT groups) successfully tolerated PAP with increased hours of documented usage. This was in contrast to children whose families declined recommended behavior therapy (CR- group), of whom 0% increased their usage of PAP. High satisfaction ratings were obtained from referring physicians and patient caregivers for children in the CR+ and BT groups.

Conclusions: The results are encouraging and support the importance of behavior analysis and therapy for increasing compliance and making the benefits of PAP available to a greater number of children.

Citation: Koontz KL; Slifer KJ; Cataldo MD; Marcus CL. Improving pediatric compliance with positive airway pressure therapy: the impact of behavioral intervention. SLEEP 2003;26(8):1010-5.
Measures

Behavior Assessment

Each child was observed during an inpatient session or outpatient visit. The caretaker was asked to use her or his customary child behavior management strategies and to put the PAP equipment on the child as trained by pulmonary, home health agency staff, or both. A task analysis of child behavior necessary for PAP compliance was developed by breaking this complex behavior into an ordered sequence of component steps. Child compliance with each step was recorded, and the percentage of steps with the child complying was calculated. A copy of the PAP Task Analysis is available from the authors and is included in the electronic version of this paper (Appendix A).

Meter Readings of PAP Usage

A retrospective analysis of patient charts was conducted. The mean hours per day of wearing PAP as read from the equipment usage meter and documented in the chart was calculated for 3 time points: (1) before behavior intervention, (2) during the behavior intervention, and (3) after the behavior intervention (mean posttreatment assessment interval was 25.7 months, SD = 22.9).

Table 1—Patient Diagnosis and Levels of Functioning

<table>
<thead>
<tr>
<th>Participant #</th>
<th>Medical Diagnoses &amp; Stressors*</th>
<th>Estimated Age, y</th>
<th>PAP setting, cm H2O</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Inpatient</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Jeunes syndrome, kidney failure, legally blind</td>
<td>6</td>
<td>8/4</td>
</tr>
<tr>
<td>2</td>
<td>Chronic pneumonia</td>
<td>Average 1</td>
<td>10/4</td>
</tr>
<tr>
<td>3</td>
<td>Myelomeningocele, obesity</td>
<td>Borderline 13</td>
<td>12/6</td>
</tr>
<tr>
<td>4</td>
<td>Myelomeningocele, acute stress reaction</td>
<td>Borderline 14</td>
<td>8/2</td>
</tr>
<tr>
<td>5</td>
<td>Cerebrovascular accident</td>
<td>Average 8</td>
<td>10/4</td>
</tr>
<tr>
<td><strong>Outpatient</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Achondroplasia</td>
<td>Average 2</td>
<td>8/4</td>
</tr>
<tr>
<td>7</td>
<td>Attention deficit disorder, oppositional defiant disorder</td>
<td>Average 7</td>
<td>14/8</td>
</tr>
<tr>
<td>8</td>
<td>—</td>
<td>Average 1</td>
<td>10/4</td>
</tr>
<tr>
<td>9</td>
<td>Myelomeningocele</td>
<td>Mild MR</td>
<td>10/4</td>
</tr>
<tr>
<td>10</td>
<td>Treacher Collins syndrome</td>
<td>Moderate MR 9</td>
<td>8/0</td>
</tr>
<tr>
<td>11</td>
<td>Turner syndrome, nasopharyngeal stenosis, hearing loss disorder</td>
<td>Mild MR 1</td>
<td>12/8</td>
</tr>
<tr>
<td>12</td>
<td>Communication disorder</td>
<td>Average 4</td>
<td>6/0</td>
</tr>
<tr>
<td>13</td>
<td>Down syndrome</td>
<td>Moderate MR 5</td>
<td>10/6</td>
</tr>
<tr>
<td>14</td>
<td>Cerebral palsy</td>
<td>Severe MR 15</td>
<td>12/6</td>
</tr>
<tr>
<td>15</td>
<td>Chronic heart and lung failure</td>
<td>Borderline 3</td>
<td>6/0</td>
</tr>
<tr>
<td>16</td>
<td>Down syndrome</td>
<td>Moderate MR 12</td>
<td>14/8</td>
</tr>
<tr>
<td>17</td>
<td>Cerebral palsy</td>
<td>Severe MR 6</td>
<td>12/6</td>
</tr>
<tr>
<td>18</td>
<td>Cerebrovascular accident; Down syndrome</td>
<td>Moderate MR 7</td>
<td>4/0</td>
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<td>19</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*diagnoses in addition to OSA. CR+ refers to positive airway pressure; MR, mental retardation.

Caregiver and Physician Satisfaction

The Caregiver Questionnaire had 8 items. It was developed by the authors to measure caregiver perception of child behavior and medical status, as well as the level of intrusiveness and difficulty of the recommended intervention. Physician satisfaction with whether or not the behavior intervention resulted in adequate PAP compliance was assessed using categorical ratings (successful or unsuccessful) of compliance and treatment efficacy. (The caregiver questionnaire is available from the authors and is included in the electronic version of this paper (Appendix B).

Intervention Procedures

Behavior Consultation

Initial compliance data were obtained during a behavior consultation session. This consisted of a structured interview and direct observation of the caregiver’s attempt to place the equipment on the child. The caregiver was asked to identify the child’s favorite activities that might be used to relax, distract, and motivate the child (small prizes, snacks, games, and videotapes). Individualized behavior recommendations were provided in writing to the caregivers. The caregivers were instructed to implement the recommendations for 1 week and to record notes on the child’s cooperation. The need for ongoing behavior therapy was determined based on the results of this initial trial. Behavior therapy was recommended for any caregiver who was unsuccessful at implementing the behavior recommendations. A retrospective analysis of patients revealed that after the behavior consultation, children and caregivers could be categorized as (1) those who effectively implemented the intervention (CR+), (2) those who were not able to effectively implement the intervention and who declined recommended behavior therapy (CR-), and (3) those who completed the recommended behavior therapy (BT). The CR+ and CR- groups received only 1 session, which included the behavior consultation and presentation of recommendations. The BT group averaged 6 sessions (SD = 3.1) with multiple sessions conducted within a 1-hour appointment.

Behavior Therapy

Children in the BT group participated in behavior-rehearsal sessions during which PAP-related stimuli were presented with gradually increasing proximity and duration but were also associated with positive events. The therapy techniques described below were integrated within the rehearsal sessions.

Positive reinforcement refers to systematic presentation of a stimulus or event contingent on a target behavior resulting in a subsequent increase in the frequency of that target behavior. Differential positive reinforcement involved consistently reinforcing some behaviors (eg, cooperation with PAP) with praise and not praising others (eg, removal of the mask). At the start of each session, the child was asked to choose 1 from an assortment of prizes or activities to earn by “listening, following instructions, and not trying to take off the mask.” Praise was provided for each step completed in the PAP task analysis. For younger or developmentally delayed children with a limited attention span and difficulty delaying gratification, an immediate and tangible reinforcer (token or sticker) was awarded, along with praise for completion of each step (stickers were exchanged for the prize at the end of the appointment). Gradually, the requirements for reinforcement were increased until the child willingly got into position, helped to put on the equipment, and quietly tolerated the mask and air pressure until either falling asleep or the session was ended by the therapist.

Graduated exposure was conducted by presenting the PAP equipment and its application 1 step at a time according to the sequence outlined in the PAP task analysis and at a pace that challenged but did not overly distress the child.

Counter conditioning was conducted by prompting and praising the child’s participation in a favorite and distracting activity (music, conver-
sation, stories, movie, or computer game). The activity was used to relax the child, then potentially distressing PAP equipment and sensations were presented 1 at a time while praising the child’s tolerance of this stimulation. This planned pairing of comforting and feared stimuli was continued until the patient comfortably tolerated all of the sensations and steps in the PAP task analysis.

Escape or avoidance prevention strategies were implemented by the therapist or caregiver to teach the child that attempts to avoid or remove the PAP equipment no longer would be effective. The child’s vocal protests were ignored. The therapist, speaking in a calm voice, intermittently reassured the child that “you can do it, you will be OK, etc.” The child’s attempts to remove the mask were physically interrupted, and the child’s hands were directed away from the mask and toward the activity being used for counter conditioning. If the child removed the mask, it was immediately put back in place by the therapist or caregiver.

**Caregiver and Staff Training**

The therapist implemented treatment during initial sessions when the child was most resistant to the PAP. At first, the caregiver and therapist worked as a team with the caregiver following instructions and demonstrations by the therapist. As the caregiver became proficient with the routine, the therapist slowly withdrew from the hands-on aspect of the treatment. Caregivers were trained to collect data on the child’s compliance with PAP, which provided a means of checking staff or caregiver compliance and identifying the parts of the protocol that were especially difficult for the caregiver. The form also prompted and guided the caregiver’s behavior in the absence of the therapist. Written behavior guidelines for helping children tolerate PAP were also given to caregivers. This information is available from the authors and is included in the electronic version of this paper (Appendix C).

**Statistical Analyses**

This study was a retrospective analysis involving a small number of patients and is therefore limited in possible type and interpretation of analyses. Descriptive statistics (means and SD) were initially used to test for between-group differences on demographic variables. Mean hours of equipment usage were analyzed using a repeated measures analysis of variance and Tukey posthoc difference testing ($P < .05$) when appropriate.

**RESULTS**

Figure 1 presents mean hours of compliance per night recorded at baseline, during treatment, and after treatment. Patients in both BT and CR+ groups displayed clinically significant gains in the amount of time PAP was worn. None of the 3 groups differed in mean hours of PAP usage at baseline, and the CR+ and BT groups did not differ significantly during the treatment and posttreatment phases (Tukey HSD test $< .05$). The CR+ group displayed significantly longer PAP usage at post-treatment when compared to the CR- group (Tukey HSD test $< .05$). Table 2 shows that after treatment, all patients in the CR+ group were compliant with PAP and displaying good OSA management (OSA had resolved in 1 patient). Of the BT patients, 8 of the 11 (73%) reportedly wore the PAP whenever sleeping. Of these 8, 1 family elected tracheostomy despite the child’s adequate compliance (participant #7), and 1 child no longer required PAP after a follow-up sleep study indicated that the OSA had resolved (participant #9). Of the 3 BT children with poor compliance, 2 displayed increases in PAP usage but not enough to effectively manage their OSA, and 1 child died in a house fire. Compliance for the CR- group was low. Of the 3 children in the CR-group, 1 child’s OSA was reportedly resolved (participant #13), 1 child died of respiratory failure (participant #16), and 1 child remained on PAP but continued to display poor OSA management.

The second column in Table 2 distinguishes between sessions required to initially obtain child compliance (number shown in parentheses) and the total number of sessions. On average, children receiving BT achieved compliance within 3 rehearsal sessions conducted during 1 to 3 appointments.

Physicians’ and therapists’ ratings were highest for patients receiving CR+, with 100% of physicians expressing satisfaction and therapists rating both child cooperation and parent follow-through as satisfactory for all. Physicians’ ratings of PAP usage were satisfactory for 8 of 11 (73%) of the BT participants. For the 3 participants receiving poor ratings (#4, 11, and 17), the behavior therapist had recorded the child’s skills as satisfactory but caregiver follow-through was poor. Only 1 (33%) of the CR-participants received a satisfactory rating of PAP usage from the physician, and the child’s OSA had resolved.

Of the 15 caregivers who experienced success, 12 responded to the satisfaction survey, and 83% of them reported following all of the behavior recommendations. They also reported immediate changes in their child’s behavior after she or he had worn the PAP on a regular basis, including improvement in mood (92%), increased alertness (83%), more restful sleep (75%), and seemingly enhanced learning abilities (58%). Of the 5 cases rated as poor by physicians, 3 caregivers responded. Two of these reported difficulties following the behavior recommendations and did not establish a nighttime routine or a reinforcement program. These 2 caregivers reported that if their child removed the mask, they often did not replace it in order to avoid a physical and emotional struggle.
The third caregiver reported that implementing the PAP routine produced an “emotional struggle” and required “too much time.” Therefore the family had chosen surgery for their child.

**DISCUSSION**

Data from pediatric pulmonary clinic records, behavior assessments, and caregiver reports were examined to determine the efficacy of behavior interventions targeting PAP compliance in children with OSA. Prior to behavior intervention, none of the children were consistently wearing the PAP equipment. After intervention, 75% of children who received behavior intervention (CR+ and BT groups) were able to successfully tolerate PAP and evidenced increased documented hours of usage. This was in contrast to children whose families declined recommended behavior therapy (CR- group), of whom 0% increased their successful usage of PAP. Both the CR+ and BT patients displayed adequate post-treatment compliance, with patients averaging approximately 8 hours and 6 hours per night of PAP use, respectively. Compliance with PAP appeared to be influenced by the fit of the equipment, the child’s adaptation to the equipment, and caregiver follow-through when the child became distressed and removed the equipment.

Compliance leading to effective OSA management was trained in a short period of time, and some patients achieved compliance with only 90 minutes of behavior consultation and written recommendations. These results are especially encouraging because the patients in this study were the most challenging cases (those who had been referred for behavior intervention for PAP noncompliance). If routinely provided prospectively, behavioral training may prevent compliance problems for many children.

This was not an experimentally controlled study. Families were not randomly assigned to groups but, instead, self-selected the behavior services they would accept. On average, children in the CR+ group were younger and appeared to have less-challenging behavior problems (parents of children with more-challenging behavior problems were offered additional behavior therapy sessions). Younger children may respond more quickly to behavior intervention because caregivers can implement the recommendations more effectively with younger children who are easier to physically guide and to block from pulling off the mask. The greater mean hours of usage for the CR+ compared to the BT group might have been a function of younger children sleeping more hours. Only a few caregivers refused BT. One common characteristic across these caregivers was their statements that the child really did not need the PAP, even after being told about the risks associated with untreated OSA.

Physicians were enthusiastic about the results of the CR+ group, with 100% of all cases described as successful. The CR+ is appealing for many reasons. First, it required only 90 minutes of consulting time, was relatively inexpensive (approximately $200-$250), and was noninvasive and children typically enjoyed the sessions. The BT was also highly regarded, and despite the fact that children in this group likely had more pervasive behavior problems, 73% of the cases were rated as satisfactory. The BT requires more time (and expense) but appears to be an effective alternative for families who require more time or assistance in learning to manage their child’s resistance to PAP. Results from the CR-group indicated that there are some patients and families (15% of our sample) who could benefit from BT but will decline the services.

In most cases, the caregivers were receptive to and satisfied with the behavior interventions. They also reported positive changes in their child’s sleep, mood, and functioning. Caregivers in the CR+ group differed from those in the BT group in terms of difficulty implementing the protocols and the amount of time they spent in treatment. When compared to the BT group, the CR+ group experienced progress with treatment almost immediately, whereas the BT group typically experienced success after 2 to 3 sessions. The majority of caregivers from both groups reported that the most helpful aspect of the program was “individually tailored treatment.” In addition to treatment for PAP, BT caregivers reported valuing the support and training of the behavior psychologist for general adult demands. A majority of caregivers in both the CR+ group and BT groups reported that the most difficult recommendation to follow was “setting up and maintaining a reinforcement system” for their child. The CR- group

Table 2—Positive Airway Pressure Compliance, Ratings and Patient Status as a Function of Intervention

<table>
<thead>
<tr>
<th>Group</th>
<th>Participant #</th>
<th>Sessions, no.*</th>
<th>PAP Compliance</th>
<th>Child Cooperation and Skills</th>
<th>Parent/Staff Follow through</th>
<th>Management of OSA</th>
<th>Patient status</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Preintervention, h/night†</td>
<td>Postintervention, h/night†</td>
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<td></td>
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<tr>
<td>BT</td>
<td>1</td>
<td>10 (4)</td>
<td>0</td>
<td>8</td>
<td>S</td>
<td>S</td>
<td>Tolerating PAP</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>7 (4)</td>
<td>1.5</td>
<td>5</td>
<td>S</td>
<td>S</td>
<td>Tolerating PAP</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>9 (6)</td>
<td>0</td>
<td>6</td>
<td>poor</td>
<td>poor</td>
<td>Tracheostomy</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>8 (3)</td>
<td>1</td>
<td>6</td>
<td>S</td>
<td>S</td>
<td>Tolerating PAP</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>2</td>
<td>0</td>
<td>7</td>
<td>S</td>
<td>S</td>
<td>Tracheostomy</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>7 (3)</td>
<td>0</td>
<td>12.7</td>
<td>S</td>
<td>S</td>
<td>OSA resolved</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>2</td>
<td>0</td>
<td>8.5</td>
<td>S</td>
<td>S</td>
<td>Tolerating PAP</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>9 (4)</td>
<td>1</td>
<td>1.5</td>
<td>poor</td>
<td>poor</td>
<td>surgery</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>5 (2)</td>
<td>0</td>
<td>3</td>
<td>S</td>
<td>poor</td>
<td>UPPP surgery</td>
</tr>
<tr>
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<td>10</td>
<td>2</td>
<td>0</td>
<td>4.5</td>
<td>S</td>
<td>S</td>
<td>Tolerating PAP</td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>3 (1)</td>
<td>4</td>
<td>8.5</td>
<td>S</td>
<td>S</td>
<td>Tolerating PAP</td>
</tr>
<tr>
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<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>CR+</td>
<td>1</td>
<td>2</td>
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<td>S</td>
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</tr>
<tr>
<td></td>
<td>2</td>
<td>6</td>
<td></td>
<td>S</td>
<td>S</td>
<td>S</td>
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</tr>
<tr>
<td></td>
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<td>8</td>
<td></td>
<td>S</td>
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<td>S</td>
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</tr>
<tr>
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<td>4</td>
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</tr>
<tr>
<td></td>
<td>5</td>
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<td>S</td>
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</tr>
<tr>
<td></td>
<td>6</td>
<td>2</td>
<td></td>
<td>S</td>
<td>S</td>
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</tr>
<tr>
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<td>7</td>
<td>3</td>
<td></td>
<td>S</td>
<td>S</td>
<td>S</td>
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</tr>
<tr>
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<td>8</td>
<td>1</td>
<td></td>
<td>S</td>
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</tr>
<tr>
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<td>9</td>
<td>1</td>
<td></td>
<td>S</td>
<td>S</td>
<td>S</td>
<td>Tolerating PAP</td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>1</td>
<td></td>
<td>S</td>
<td>S</td>
<td>S</td>
<td>Tolerating PAP</td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>1</td>
<td></td>
<td>S</td>
<td>S</td>
<td>S</td>
<td>Tolerating PAP</td>
</tr>
</tbody>
</table>

*The number in parentheses is the number of sessions necessary for the child to become 100% cooperative with positive airway pressure (PAP), the other number is the total behavior therapy sessions provided.
†For preintervention and postintervention columns, the data are displayed by mean number of hours per night that PAP was worn during sleep hours. Data for hours spent wearing the PAP were taken from clinic meter readings.
OSA refers to obstructive sleep apnea; BT, the group receiving consultation and recommendations plus a course of behavior therapy; S, satisfactory; UPPP, uvulopalatopharyngoplasty; CR+, the group receiving a 1.5-hour consultation and recommendation session; CR-, the group for whom behavior therapy was recommended after the consultation and recommendations but the family did not follow-up.
reported their difficulties as "recommended strategies were too difficult to put into place with my family," “partner would not follow techniques,” “child displayed no progress, so I discontinued protocol,” and “other issues demanded my full attention.”

Conclusions drawn from this retrospective descriptive analysis are limited by the small sample size and lack of random assignment of participants to groups. Furthermore, measuring compliance using a machine definition (i.e., the PAP hour meter) may overestimate usage if the PAP machine is operating even when the patient is not wearing it. Although these data were cross-referenced with chart notes, caregiver reports, and physician subjective ratings, it is possible that compliance was lower than reported.

These clinical outcome data support the use of behavior intervention for increasing child and caregiver usage of PAP. These approaches appear to be effective with a broad range of pediatric patients regardless of age, presence of preexisting behavior problems, or developmental disabilities. The results support the utility of behavior analysis and therapy for improving compliance, thereby making the benefits of PAP available to a greater number of children. To further document the efficacy of behavior methods in improving compliance, future studies should utilize a larger, randomized, prospective design with a diverse group of children with sleep-related respiratory disturbances and should systematically track the cost-effectiveness of such interventions so that evidence-based literature will exist to support the use of these strategies.

ACKNOWLEDGEMENT
This study was funded, in part, by the Kennedy Krieger Institute and Johns Hopkins University School of Medicine Mental Retardation/Developmental Disabilities Research Center Grant (NICHD No. HD24061)

REFERENCES

APPENDIX A

Bilevel PAP Task Analysis
1. The child sits on bed or stretcher.
2. The child cooperates with having the Bilevel PAP cap placed on the back of head.
3. The child lies in the supine position on the bed/stretcher.
4. The child remains supine and calm while the mask (not attached to the hose or cap) is placed in position on the face for 5 seconds.
5. The child remains supine and calm while the mask (not attached to the hose or cap) is placed in position on the face for 10 seconds.
6. The child remains supine and calm while the mask (not attached to the hose or cap) is placed in position on the face for 1 minute.
7. The child remains supine and calm while one side of the mask is attached to the cap. **Prior to next step, the mask will need to be connected to the tube and the tube will need to be connected to the machine.
8. The child remains supine and calm while the mask (attached to hose and one side of the cap) is placed in position on the face and while the air is turned on for 3 seconds.
9. The child remains supine and calm while the mask (attached to hose and one side of the cap) is placed in position on the face and while the air is turned on for 5 seconds.
10. The child remains supine and calm while the mask (attached to hose and one side of the cap) is placed in position on the face and while the air is turned on for 10 seconds.
11. The child remains supine and calm while the mask (attached to hose and one side of the cap) is placed in position on the face and while the air is turned on for 1 minute.
12. The child remains supine and calm while the mask is placed in position on the face and is connected to the cap on both sides.
13. The child remains supine and calm while the mask (attached to hose and both sides of the cap) is placed in position on the face and while the air is turned on for 1 minute.
14. The child remains supine and calm while the mask (attached to hose and both sides of the cap) is placed in position on the face and while the air is turned on for 5 minutes.
15. The child remains supine and calm while the mask (attached to hose and both sides of the cap) is placed in position on the face and while the air is turned on for 10 minutes.
16. The child remains supine and calm while the mask (attached to hose and both sides of the cap) is placed in position on the face and while the air is turned on for 15 minutes.

APPENDIX B
Caregiver Satisfaction Questionnaire
1) Is your child still wearing the Bilevel PAP?
   (If yes) How are they doing?
   WEARING Bilevel PAP: a) set up a bedtime routine for your child b) put up reinforcement system c) put the mask back on each time your child removed it (If no): Why?
   (Permit caregiver to generate. Sample responses include: OSA corrected through surgery; was too difficult to get them to wear it, so we stopped; physician said s/he no longer needed to wear it….)

2) Did you notice any changes in your child’s behavior after s/he was tolerating the Bilevel PAP regularly?
   a) Sleeping better b) Improved mood c) Learning more d) Seemed more alert e) No differences noted

3) Do you believe you could have been successful in getting (child) to wear the Bilevel PAP without our help?
   Yes No (allow caregiver to explain response)

Level of Intrusiveness
4) Were you able to follow the recommendations given by the behavioral therapist? For example, were you able to:
   a) Set up a bedtime routine for your child b) Set up reinforcement system c) Put the mask back on each time your child removed it (If not): Which of the following best describes why you believe it was difficult to use the Bilevel PAP?
   a) Life is too hectic/other issues demanded my full attention b) Recommended strategies were too difficult to put into place with my family c) Techniques were too time-consuming d) Partner would not follow techniques e) Child displayed no progress, so I gave up

5) What was the most helpful aspect of our service?
   a) Support with problem behaviors b) Access to/increased communication with medical personnel c) Education about Bilevel PAP d) Individually-tailored treatment for my child and family e) Other (________________________________________)

6) What was the least helpful aspect of our program?
   a) Took too much time to complete b) Difficult to get an appointment c) Other (________________________________________)

7) Do you believe that the behavioral psychology department provides an important service for patients needing to wear Bilevel PAP?
   a) Yes, definitely b) Yes, for the most part c) No, not really that important d) No, not at all important

8) How can we improve our service?
   Let parent/caregiver generate….

Is your child in school?
What kind of school program does your child attend? (special education/regular programming)
APPENDIX C

General Behavior Guidelines for Helping Children Tolerate CPAP/Bilevel PAP

These are general guidelines to be followed at home. Persistent noncompliance may indicate additional problems. If this is the case, it is strongly recommended that a consult be arranged with a behavioral psychologist or someone trained to analyze and change behavior.

1) It is very important to develop a routine whenever your child is getting ready for sleep. This includes putting on pajamas, placing him/her in a crib or bed, playing with a special toy, and other activities that already have been established.

2) Turn on machine as soon as you enter his/her room.

3) When your child is in bed, rub his/her arms, and talk in a low voice to create a calm and relaxing environment.

4) Present the mask with the cap attached in front of your child. Never place any of the equipment on from behind. The goal is to teach your child that this equipment is part of bedtime routine so it’s important that everything is predictable and done consistently.

5) Slowly place the mask on the nose and then place the cap on the head. Fasten the strap to the mask (only undo one strap so it can be fastened quickly when the cap is placed on your child’s head). Depending upon your child’s age, it may be developmentally appropriate for your child to be involved in placing the mask or adjusting it. Older children often appreciate the opportunity to assist in their own medical care.

6) If your child struggles, use one hand to block his/her hands and keep them down. With the other hand, keep the mask over his/her nose. As s/he starts to calm down, slowly lift your hand and proceed with putting on the cap and place the mask so it is in the proper position over the nose. In the case of older children, it might not be possible to effectively physically block them from removing the mask. Most importantly, if the mask is removed, it must be put on again immediately.

7) Your child may cry when the equipment is placed on him/her. However if s/he is not grabbing at the equipment and begins to breathe thru the mask when it is put on, you should begin rubbing his/her arms and speak softly. You can place a plush toy around his/her arms when the equipment is on and your child is calm. For older children, it is suggested that you engage them in a favorite quiet activity (e.g., reading a favorite book, or watching a preferred movie or TV program). Such quiet time activities are not only a reward for tolerating the mask, but may also act as a useful distraction.

8) If your child struggles again (which will probably occur in the beginning), do not look directly at him/her, animate your face, or speak to him/her. Try to keep a neutral face and proceed with blocking your child’s arms and get the equipment on him/her quickly and safely.

9) When the equipment is on again, then you can rub your child’s arms, smile and soothe your child. Proceed with the favorite activity (e.g., reading books, talking, etc) only when s/he is not touching the mask.

10) If the equipment comes off because your child rolls or pulls it off while s/he sleeps, follow the procedure as outlines above. It is critical that the equipment gets placed back on your child after each time it comes off regardless of whether s/he removed it or it comes off during movement while asleep. CPAP and bilevel PAP machines can be equipped with an alarm that will sound when the mask comes off. Many caregivers have found these alarms quite helpful in monitoring compliance and ensuring that the mask is replaced immediately if it happens to be removed.

11) Lastly, be sure that your child knows that only the caregiver is to remove the mask. For older children, or children who are physically able to safely remove the masks, you may make arrangements that they can take the mask off, but only after a caregiver instructs them to do so.