

BARRIERS AND CORRELATES OF ADHERENCE IN PEDIATRIC
OBSTRUCTIVE SLEEP APNEA

By

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Abstract of Dissertation Presented to the Graduate School
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The use of Continuous Positive Airway Pressure (CPAP) treatment for youth with Obstructive Sleep Apnea (OSA) is effective at relieving symptoms of the disorder and preventing future physical, emotional, and behavioral complications. However, the device must be used consistently in order for benefits to be realized. Non-adherence to medical treatment is prevalent among youth with chronic illness, yet little is known regarding adherence to CPAP in pediatric OSA. The factors that contribute to CPAP non-adherence are as of yet unclear, and specific correlates of adherence are unknown in this population. Thus, the current study attempts to add to the literature by addressing these issues. Using a sample of 51 youth (age eight to 17 years) recruited from a pediatric sleep specialty clinic, the aims of the current study were to: 1) present descriptive data regarding CPAP adherence in youth with OSA; 2) develop a psychometrically sound measure of barriers of adherence to CPAP use for youth with OSA; 3) identify psychosocial correlates of adherence to CPAP; and 4) examine the role of health beliefs with regards to youth CPAP adherence. Results indicated that adherence to CPAP is indeed poor: on average, 3.35 hours per night. The adherence barriers measure demonstrated excellent psychometric properties. Psychosocial

functioning was not significantly related to CPAP adherence. A Health Belief Model was upheld with regards to CPAP adherence, with barriers to adherence being the greatest predictor of CPAP usage. This study provides information that can aid healthcare practitioners in identifying patient-specific issues and inform researchers in developing targeted interventions to enhance CPAP adherence for youth with OSA.

CHAPTER 1 INTRODUCTION

Breathing during sleep occurs on a continuum ranging from unobstructed respiration to severe obstruction. Sleep-Disordered Breathing (SDB) is a term referring to this spectrum of disrupted breathing during sleep. The most severe disorder of this spectrum is Obstructive Sleep Apnea (OSA), a sleep disorder that is distinguished by multiple episodes of extended upper airway obstruction resulting in arousals from sleep. Prevalence of the disorder is approximately 1-3% of youth, with bimodal peak onset occurring between ages 2-6 and in adolescence (Meltzer & Mindell, 2006; Mindell & Owens, 2003). Risk factors for OSA are twofold, and include upper airway obstruction, such as enlarged tonsils and adenoids, or decreased upper airway size, typically from obesity. Prevalence of SDB in overweight children is as high as 13-33% (Beebe et al., 2007). Typical presentation of OSA includes labored breathing during sleep, apneic episodes, and restless sleep (Meltzer & Mindell; Mindell & Owens). A variety of secondary symptoms related to OSA are known to occur, including mood lability, behavior problems, Attention-Deficit/Hyperactivity Disorder (ADHD)-like symptoms, neuropsychological deficits, and academic problems (Halbower, Ishman, & McGinley, 2007).

Treatment for OSA is important in order to alleviate the negative physical symptoms and complications resulting from the disorder, as well as to prevent and ameliorate the potential secondary effects. The primary treatment for OSA is an adenotonsilectomy, the removal of the child's tonsils and adenoids. While this treatment is effective in approximately 70-90% of cases, it is not useful for cases of the disease not caused by enlarged tonsils or adenoids, such as obesity-related OSA (Meltzer &

Mindell, 2006; Mindell & Owens, 2003). For these children, an effective treatment is Continuous Positive Airway Pressure (CPAP), a machine that emits a flow of air to maintain open airways during sleep. While not curative, CPAP has been shown to be effective at improving both objective and subjective symptoms of OSA in children (Marcus et al., 2006). However, the device must be used consistently in order for benefits to be realized. Even missing a single night's use can cause significant health and behavioral consequences (Dinges & Weaver, 2007).

Unfortunately, adherence to CPAP is often problematic. Given the nature of the treatment regimen for OSA, it is not surprising that adherence is poor. Side effects are common, including discomfort, nasal symptoms, chafing, and irritation. Children may develop anxiety related to CPAP therapy due to the noise of the machine, the uncomfortable sensations of wearing the mask, or feelings of claustrophobia (Haynes, 2005; Slifer et al., 2007). The most common adverse effects reported by families of children using CPAP include equipment problems, difficulties tolerating the mask, and nasal symptoms like congestion (Marcus et al., 2006).

Statistics estimate that approximately 50% of both adult and pediatric patients are non-adherent with their medical treatment (DiMatteo, Giordani, Lepper, & Croghan, 2002; Kyngas, Kroll & Duffy, 2000). Adherence is typically defined as the correspondence between a patient's health care behavior and treatment recommendations given by health care providers (i.e., Haynes, 1979). More recent conceptualizations view adherence as an active, voluntary, and collaborative process of health-related behaviors (Kyngas et al.; Sawyer & Aroni, 2003). Historically, adherence was thought of as a dichotomy; either one was adherent to treatment recommendations,

or one was not adherent. However, adherence is now considered a continuum of behaviors ranging from completely abstaining from treatment recommendations, to participating in some aspects of the treatment regimen, to using all medications and treatments as prescribed (Julius, Novitsky, & Dubin, 2009). While the relationship between adherence and health outcome is not straightforward, consequences of non-adherence are numerous. Non-adherence can lead to incorrect diagnosis and unwarranted treatments, excessive use of emergency care, increased health care costs, as well as increased symptom severity, poorer health status, and reduced quality of life. (Bender & Bender, 2005; DiMatteo, et al.; Sawyer & Aroni).

Youth Adherence to CPAP

As many as 25-50% of adults are non-adherent with CPAP treatment (Olsen, Smith, & Oei, 2008). As previously stated, it is known that adherence is commonly problematic in children and adolescents with other chronic illnesses. These facts indicate that youth with OSA may also be at risk for non-adherence. Yet, a comprehensive literature review revealed only three studies that systematically examined adherence in children and adolescents prescribed CPAP therapy. Uong and colleagues (2007) evaluated 45 children age six to 18 years with OSA who continued to have symptoms after adenotonsilectomy. The authors used electronic monitoring (meter readings from the CPAP device) to measure adherence, and found that 85% of youth used CPAP at least four hours per night. On average, participants used their CPAP seven hours per night, and approximately five nights of the week. While these rates of adherence appear high, given that children in the age range of this study require between nine and 12 hours of sleep per night (Meltzer & Mindell, 2006), it is likely that these children were not using the device for a significant portion of the night's duration.

Additionally, adherence data were only available from a segment (59%) of the already small sample.

The second study of youth adherence to CPAP was a prospective study examining 30 children two to 14 years of age with newly diagnosed OSA (Marcus et al., 2006). Youth in this study used their CPAP on average 5.3 hours per night (based on electronic meter readings). Parents demonstrated an inaccurate perception of their child's CPAP use, with subjective reports of adherence averaging 7.1 hours of use per night. Additionally, 78% of parents reported that their child did not use the machine every night. This study illustrates that youth are not using CPAP for an adequate amount of time per night, while parents may not be aware of the extent of their child's non-adherence.

The third study was done by O'Donnell and colleagues (2006) and investigated electronic meter adherence in 50 children (mean age of ten years). Authors found that 76% of youth in the sample used their CPAP for at least half the days of the week, though "use" was defined as a minimum of 1 hour per night. Overall mean daily use was 4.7 hours, while the average use time was 6.3 hours per night when only considering days that the CPAP was used. These data indicate that youth are not using their CPAP for a significant number of nights per week, and when they do use their CPAP, they are not using it for the entire night.

Overall, the results of these three adherence studies suggest that children with OSA are not using their CPAP as recommended. However, the generalizability from only a few studies with small samples is very limited. Thus, while these studies provide important preliminary data, more information is needed regarding rates of adherence in

youth with OSA. The current study attempts to fill this gap by providing information regarding rates of adherence to CPAP in a sample of youth with OSA.

Barriers to Adherence

Knowledge of a patient's non-adherence is important, but is certainly is not sufficient to explain children's adherence to recommended medical treatments. In order to help patients to become more adherent, it is necessary to understand specific barriers to adherence. Identifying barriers to adherence is important for both research and practice, for example, to aid in the development of empirically-based intervention programs, to alert healthcare professionals to a patient's risk for non-adherence, or to help providers identify and address specific issues salient for the individual patient.

While assessing barriers to adherence is crucial for healthcare providers and clinical researchers, no tools exist with which to assess barriers to CPAP use in youth with OSA. Several general, as well as disease-specific, measures of barriers to adherence have been developed for youth in the extant literature. Generic measures, such as the *Illness Management Survey* (Logan, Zelikovsky, Labay, & Spergel, 2003), created for use in a variety of medical conditions, have been shown to adequately identify barriers, and demonstrate a relationship between number of barriers and levels of adherence. Additionally, their global focus allows healthcare professionals to use one tool for a variety of patients regardless of specific illness, and allows for comparison across groups of youth with various illnesses in research studies. However, these generic measures often focus on topics such as oral medication use that are not salient to children with OSA, and fail to fully encompass the complexities of the CPAP regimen.

Disease-specific measures have also been designed for various medical populations. One example is the *Parent and Adolescent Medication Barriers Scale*,

designed to examine perceived barriers to medication adherence in youth who have undergone organ transplants (Simons & Blount, 2007). Disease-specific measures have the advantage of being tailored to the population for which it was designed, obtaining barriers unique to the specific illness and each aspect of the treatment regimen. Unfortunately, no tools assessing barriers of adherence have been created for the CPAP regimen. Thus, a precedent and a need exist for the creation of a barriers measure for CPAP use in youth with OSA.

Barriers to CPAP Adherence.

There are a number of potential barriers to adherence that families may face with regards to their child's medical treatment regimen. Barriers to adherence may be real or perceived and are specific to the individual; many patients struggle with more than one barrier (DiMatteo, et al., 2002; Logan et al., 2003; Rudy, Murphy, Harris, Muenz, & Ellen, 2009). Various studies have examined the relationship between barriers and adherence to medical treatments, and have found that the greater number of barriers endorsed is related to poorer rates of adherence (MacNaughton & Rodrigue, 2001; Marhefka et al., 2008; Modi & Quittner, 2006; Rhee, Belyea, Ciurzynski, & Brasch, 2009).

No studies have systematically examined barriers to CPAP adherence in youth with OSA. However, studies have examined barriers to CPAP use in adult patients, primarily focusing on side effects and perceived benefit from treatment. More patient-reported side effects were associated with poorer treatment adherence, with the most common reported being skin irritation, congestion, and mask air-leaks (Olsen, 2008). A large study monitored 140 adults with OSA and found that those patients classified as "intermittent" CPAP users reported more adverse effects of CPAP use such as poor

sleep, feeling uncomfortable, claustrophobia, and congestion (Aloia, Arnedt, Stanchina, & Millman, 2007). Additionally, these patients also noted less improvement in symptoms and felt that the treatment was too burdensome, compared with patients who used their CPAP regularly. Indeed, perception of benefit from CPAP has been found to be a consistent barrier to adherence, with better rates of adherence associated with patients who endorse greater perceived improvement in both daytime and nocturnal sleep-related symptoms, as well as improved overall daily functioning (Olsen, Smith & Oei, 2008; Weaver, 2006). Similarly, a study examining the Health Belief Model in regards to CPAP use found that components of this model served as predictors of adherence, including perceived benefit of treatment and self-efficacy (Olsen, Smith, Oei, & Douglas, 2008). Finally, a study of 70 adult patients with OSA showed that greater disease severity, including excessive daytime sleepiness and the Apnea-Hypopnea Index (AHI), was associated with better treatment adherence (Yetkin, Kunter, & Gunen, 2008). The authors posit that patients who are less impaired perceive less improvement in symptoms from CPAP use, and thus are less satisfied with their treatment.

While the adult literature is informative, it does not necessarily reflect the barriers to adherence that pediatric patients with OSA may experience. There are numerous differences between adult and pediatric disease self-management (Hommel, Mackner, Denson, & Crandall, 2008). For example, children and adolescents are experiencing immense developmental changes, and their accompanying challenges, that potentially make adherence more complex than for adults. Family factors must be considered when examining adherence in youth. The level of responsibility for care is changing throughout childhood as children mature, while adults tend to be primarily responsible

for their own care. Finally, developmental and cognitive functioning must be taken into consideration with youth, as the level of illness-related knowledge and specific health-beliefs are constantly changing throughout childhood, while these are more established in adulthood. For these reasons, rather than simply make inferences from the extant adult literature, it is necessary to assess pediatric-specific barriers to adherence.

Development of a Measure of Barriers to CPAP Adherence.

Given the importance of identifying barriers to adherence and the lack of a disease-specific screening tool for youth with OSA, the current study attempts to develop a psychometrically sound measure with which to assess child and family barriers to CPAP adherence: the *Adherence Barriers to CPAP Questionnaire* (ABCQ). As previously discussed, there are a variety of variables that may act as barriers to adherence. Thus, the initial conception of the measure was developed based on a comprehensive review of the extant literature regarding barriers to adherence in other pediatric chronic illnesses, which revealed several categories of barriers that seem to be most common for youth and families. These categories include: side effects, time, forgetfulness and daily hassle, attitudes and beliefs, healthcare provider relationships, psychological and behavioral concerns, social support, and equipment problems and environmental factors.

Side effects. Aversive effects of medications or treatments can contribute to non-adherence. Children may be especially susceptible to these effects, because unlike adults, they may be unable or unwilling to look past the negative immediate impact in order to achieve long-term health benefits. A primary reason that children with CF and asthma reported for not taking their medications was unpleasant taste (Modi & Quittner, 2006). The fear of experiencing more adverse effects of a treatment regimen can be

cause for alarm in both children and caregivers, and potentially lead to discontinuation or alteration of treatment. Indeed, over 80% of a sample of caregivers of inner-city children with asthma endorsed concerns regarding the serious side effects of medications (Leickly et al., 1998).

Time, forgetfulness & daily hassle. A review of reasons for non-adherence found that patients endorsed forgetting as the most common reason for not taking medications (Osterberg & Blaschke, 2005). The time-consuming nature of many chronic illness regimens, coupled with the organization and planning required to follow treatment instructions, may create difficulties for busy families to appropriately manage their child's medical care. Difficulties with time management are frequently cited as contributing to non-adherence (i.e., Modi & Quittner, 2006). A study of 182 children with HIV found that 45% of caregivers reported that disorganization, such as making the required changes in daily routine, was a significant obstacle to adherence (Marhefka et al., 2008).

Attitudes & beliefs. Attitudes and beliefs have been identified as contributors to health behaviors. Factors such as self-efficacy for managing an illness, perceived severity or consequences of the illness, and perceived benefits of treatment have all been examined in the literature for their role in predicting adherence. For example, adolescents who feel confident in their ability to manage their symptoms are more likely to be adherent to their treatment regimen, as found in studies of teens with asthma and HIV (Rudy et al., 2009; Zebracki & Drotar, 2004).

Healthcare provider relationships. The role of the healthcare provider is multifaceted. Healthcare providers (e.g., physicians, nurses, dieticians) may prescribe

medications and offer treatment recommendations, act as health educators, and impart a great influence in adherence. Provider-controlled factors such as prescribing a less complex treatment regimen, offering clear explanations of treatment rationale and potential side effects, and integrating medical treatment into a patient's lifestyle have all been associated with better adherence (Osterberg & Blaschke, 2005). Moreover, the relationship between provider and patient is important. A study of adolescents with severe asthma found that a stronger therapeutic alliance, defined as shared goals and mutual positive regard between a patient and physician, was associated with more adherence behaviors (Gavin, Wamboldt, Sorokin, Levy, & Wamboldt, 1999). Factors that have been found to play a role in establishing a positive therapeutic alliance are good patient-provider communication and encouraged active patient participation in care (DiMatteo, 2004; Kyngas et al., 2000).

Psychological & behavioral concerns. Youth with chronic illness have been shown to be at greater risk for developing psychological difficulties compared to healthy peers (Blackman & Gurka, 2007; Quittner, Barker et al., 2008). Correlates of these behavioral and emotional problems may play a role in adherence to treatment; for example, youth with ADHD may be less able to complete their treatment regimen due to difficulties with organization and attention. Social stigma may also play a role in adherence. Youth may feel that adhering to their treatment recommendations acts as a reminder that they are different from healthy children, or feel embarrassed to take medications when doing so would disclose their illness to their peers (Bender & Bender, 2005).

Social & family support. When considering adherence in pediatric patients, it is important to take into account family factors. While division of responsibility for the treatment regimen varies across families, typically parents are primarily responsible when the child is young, and gradually shift responsibility for treatment as the child matures (Williams et al., 2007). Greater parental supervision was associated with better adherence to nebulizer treatments in a sample of adolescents with CF (Modi, Marciel, Slater, Drotar, & Quittner, 2008). Not just practical support (e.g., directly administering or supervising treatment) but also emotional support has been shown to be positively related to treatment adherence. Family factors associated with greater adherence include positive family climate, an open relationship amongst family members, parental warmth, and positive family interaction patterns (DiMatteo, 2004b; Kyngas et al., 2000). One review found that patients in more cohesive families had almost two times greater adherence rates compared to patients from families characterized by high conflict (DiMatteo, 2004a). Overall, it is important to note that the medical treatment regimen impacts all aspects of family life, and a family's level of functioning has the potential to either aid or hinder adherence to the treatment regimen.

Equipment problems & environmental factors. Difficulties such as broken equipment or an ill-fitting facemask may be potential contributors to poor adherence to the treatment regimen. One study of youth CPAP use found that 10-21% of families reported equipment problems, such as the CPAP device not working properly or worn-out tubing (Marcus et al., 2006). Additionally, environmental factors such as a lack of storage space for the CPAP machine may also be prohibitive to proper adherence.

Correlates of Adherence

As illustrated by the number of potential barriers to adherence, many variables have been examined as to their relation with treatment adherence. Yet, the factors that contribute to non-adherence are still unclear: research has shown no single set of predictors to consistently explain non-adherence in all cases. Furthermore, no studies have empirically investigated relationships between adherence and predictive factors in youth with OSA. This highlights the need for further research into correlates of adherence to pediatric CPAP use. Two such variables found to be correlates of adherence that have been explored in other pediatric chronic illnesses are psychosocial functioning and health beliefs.

Psychosocial Correlates of Adherence

Caregivers of youth with disordered breathing in sleep (like OSA) rate their child as experiencing more internalizing and externalizing behavior problems than do parents of healthy children (Mitchell & Kelly, 2006). Additionally, symptoms of inattention and hyperactivity are often reported in children with sleep disordered breathing (Chervin et al., 2002). Claustrophobic reactions to CPAP treatment are common, occurring in as many as 11-28% of adult patients (Lewis, Seale, Bartle, Watkins, & Ebden, 2004). Given the nature of these internalizing and externalizing difficulties (i.e., loss of interest or pleasure, irritability, difficulty concentrating, difficulty organizing tasks), it may be that patients experiencing these symptoms have a harder time adhering to their medical treatment. Conversely, these symptoms may be a result of inadequate adherence resulting in subsequent medical complications and poor sleep. In other chronic illnesses, psychosocial factors have been found to be related to treatment adherence. For example, a review of depression in children and adolescent patients with cystic

fibrosis found that mood symptoms were negatively related to treatment adherence (Quittner, Barker et al., 2008). Studies of adults with OSA have typically failed to find a significant association between anxiety or depression and adherence (Lewis et al., 2004; Stepnowsky, Palau, Gifford, & Ancoli-Israel, 2002; Wells, Freedland, Carney, Duntley, & Stepanski, 2007), with the exception of greater claustrophobia associated with poorer adherence (Weaver, 2006). However, the nature of the relationship between internalizing and externalizing symptoms with adherence in youth with OSA is currently unknown.

As previously discussed, family factors are important when examining adherence to medical treatment. While family functioning has not been examined in youth with OSA, better family functioning has been significantly positively correlated in youth with other chronic conditions, such as diabetes (Pereira, Berg-Cross, Almeida, & Machado, 2008) or Juvenile Rheumatoid Arthritis (Kyngas et al., 2000). Taken together, psychosocial functioning may indeed play a role in adherence in youth with OSA, and research is needed in order to examine these relationships.

Health Beliefs and Adherence

The Health Belief Model is a theoretical model that has been proposed to explain how beliefs and attitudes act as a determinant of treatment adherence through a cost-benefit analysis. In this model, the patient's perceived susceptibility (the extent to which one feels that one is likely to be impacted by an illness) and perceived illness severity is factored into a comparison of the potential benefit of treatment against barriers to treatment (DiMatteo, Haskard, & Williams, 2007; Leickly et al., 1998). The Children's Health Belief Model is adapted from this model, and takes into account developmental, parent, and family factors (Bush & Iannotti, 1990). These models have been proposed

to explain non-adherence in pediatric chronic illness patients. For example, one study of adolescents with asthma, HIV, and Inflammatory Bowel Disease examined teens' health beliefs and found that those patients who felt that treatment offered greater positive benefits, expected fewer negative outcomes, and had stronger intentions to adhere to treatment had greater actual adherence (Reikert & Drotar, 2002). Moreover, these health beliefs were found to account for 22% of the variance in treatment adherence beyond that explained by demographic or disease-specific variables.

If patients do not perceive a need for a medical treatment such as CPAP, they may be less likely to adhere to their treatment. Parents who believe that their child's illness is severe or has the potential to cause adverse health effects are more likely to take action to manage their child's health condition (DiMatteo, 2004b). Additionally, motivation to adhere has been shown to be low for patients who perceive little benefit from their treatment (Abbott & Gee, 1998).

In patients with OSA, results are mixed with regards to the relationship between disease severity and adherence. For example, one study of youth with OSA found no difference between adherent and non-adherent patients in terms of either OSA severity (measured by various polysomnography indices) or subjective symptoms (e.g., daytime sleepiness) (Marcus et al., 2006). In contrast, Uong and colleagues (2007) found that youth who were classified as adherent (defined as using CPAP at least 4 hours per night for 5 or more nights per week) had higher baseline OSA severity and demonstrated greater improvement in symptoms while being treated. In adults with OSA, greater objective (i.e., Apnea-Hypopnea Index) and subjective (i.e., daytime sleepiness) indices of disease severity have both been found to be associated with

better CPAP use (Weaver, 2006; Yetkin et al., 2008). Given these previous findings, additional inquiry into the relationship between health beliefs and adherence is warranted. Yet, no studies have examined the role of the Health Belief Model in predicting adherence to CPAP in youth with OSA.

Current Study Aims and Hypotheses

The current literature for pediatric OSA and CPAP adherence is extremely limited, with only three studies (Marcus et al., 2006; O'Donnell, Bjornson, Bohn & Kirk, 2006; Uong, Epperson, Bathon & Jaffe, 2007) systematically examining rates of adherence in youth with OSA, despite evidence from the adult OSA literature and knowledge from other chronic illness populations that non-adherence is a significant problem.

Additionally, no measures currently exist to evaluate barriers to adherence with CPAP, which could aid practitioners and researchers in recognizing and ameliorating various factors that may obstruct treatment adherence. Finally, few studies have investigated correlates of adherence in youth with OSA, and a need exists to determine the relation of psychosocial factors and health beliefs with rates of adherence. Thus, study aims and hypotheses were as follows:

Aim 1 – CPAP Adherence

Present descriptive data regarding CPAP adherence in a sample of youth with OSA.

Hypothesis 1.1: Not applicable. Levels of electronic download adherence data for youth in the current study will be presented.

Aim 2 – Psychometric Properties of the ABCQ

Demonstrate the psychometric properties of the ABCQ.

Hypothesis 2.1: Internal consistency. The ABCQ will demonstrate adequate internal consistency, with a Cronbach's alpha level at or above .70 (Kline, 1986).

Hypothesis 2.2: Test-retest reliability. Given the brief time period between assessments and the nature of potential barriers, it is anticipated that the ABCQ will demonstrate a stable pattern of results at two-week post-test, resulting in a moderate-to-high correlation of greater than .60.

Hypothesis 2.3: Convergent validity. The ABCQ will be compared to other measures known to assess variables hypothesized to be related to adherence barriers. It is hypothesized that the ABCQ scores will correspond to scores on these other measures. Specifically:

2.3a: A significant correlation will be found between barriers to adherence and actual adherence (electronic download data). Specifically, more barriers to adherence will be associated with poorer adherence rates.

2.3b: A significant correlation will be found between barriers to adherence and health-care satisfaction, with more barriers to adherence associated with lower ratings of health-care satisfaction, as assessed by the PedsQL Healthcare Satisfaction Generic Module.

2.3c: A significant correlation will be found between barriers to adherence and the negative outcome expectancy subscale of the Beliefs About Medications Scale. More barriers to adherence will be associated with greater negative outcome expectancy.

Aim 3 – Psychosocial Functioning

Identify psychosocial correlates of adherence to CPAP.

Hypothesis 3: Variables related to psychosocial functioning will be significantly associated with rates of adherence, after controlling for demographic variables such as age and gender.

3a: Families with poorer family functioning (general functioning as measured by the Family Assessment Device) will have poorer adherence.

3b: Youth with greater levels of internalizing symptoms (assessed by the BASC) will have poorer adherence.

3c: Youth with greater levels of externalizing symptoms (assessed by the BASC) will have poorer adherence.

Aim 4 – Health Beliefs

Investigate the predictive role of the health beliefs with regards to youth CPAP adherence.

Hypothesis 4: Variables conceptualized as part of the Health Belief Model (e.g., perceived disease severity, perceived susceptibility, perceived benefit of treatment, and barriers to adherence) will significantly be associated with rates of adherence, after controlling for demographic variables such as age and gender.

4a: Greater caregiver and youth perceptions of disease severity, illness susceptibility, and benefits of treatment, as well as fewer barriers to adherence will be predictive of greater rates of adherence.

CHAPTER 2 METHOD

Participants

A total of 51 children and adolescents aged 8-17 years with OSA and their caregiver were recruited from an academic medical center sleep specialty clinic in rural Florida. Fifty-three families were contacted for participation in the study, of which all agreed to participate (100%). Of these families, four (7.5%) were contacted at multiple clinic visits, initially declining participation due to lack of time while later agreeing to participate at a subsequent appointment. Additionally, two families (4%) were excluded from the study as the children did not meet eligibility criteria.

Inclusion Criteria

Eligibility for study participation included: 1) youth between the ages of 8 to 17 years, 2) both caregiver and youth willing to participate, 3) confirmed diagnosis of OSA for at least 6 months by overnight polysomnography (PSG) in a sleep lab, 4) physician prescribed nightly CPAP treatment regimen for at least 6 months, 5) followed by a case manager from a home health care company that provides patients with CPAP machines with electronic-meter capabilities.

Exclusion Criteria

Youth and parents were excluded from study participation due to the following factors: 1) significant cognitive and/or reading impairment that precluded completion of study measures, 2) non-English speaking family, and 3) major comorbid medical diagnoses unrelated to the child's OSA (i.e., cerebral palsy, cancer).

Experimental Design

This study utilized a cross-sectional design. A power analysis was conducted to obtain an optimal number of participants in order to afford sufficient power for planned statistical analyses (Faul, Erdfelder, Lang & Buchner, 2007). Several studies examining correlates of adherence with adult OSA patients found effect sizes ranging from medium to large ($r = .27- .56$; Olsen, Smith, Oei, & Douglas, 2008; Yetkin et al., 2008). Therefore, using an effect size estimation based on planned contrasts to yield a medium level effect ($f^2 = .20$), results indicate that a sample size of 65 will produce a power of .80, as recommended by Cohen (1992). Given the final sample of 51 participants and an anticipated medium effect size, calculated power is actually .66.

Procedure

This study was approved after review by the University of Florida Institutional Review Board (IRB). Participation in the study took place at the child's regularly scheduled clinic appointment and lasted approximately 30 minutes. Two weeks after this study visit, families were sent an additional questionnaire (the ABCQ), along with a self-addressed stamped envelope, to complete and return via mail.

Trained members of the research team identified potential participants (based on eligibility criteria stated above) with assistance from the Pediatric Pulmonary Clinic staff. To ensure that the study team did not approach patients who did not meet inclusion criteria for the study, a Waiver of HIPAA Privacy Authorization was obtained by the IRB to allow the research team to obtain patients' names, ages, and diagnosis information in order to identify potential participants. Additionally, a letter was sent to all families in the sleep clinic prescribed CPAP describing the research study and providing information

on how to participate, if desired (a Waiver of Informed Consent was obtained by the IRB for this purpose).

After obtaining permission from the family to speak to them about a research study, research team members met with the family in a private clinic room to provide study information details and an opportunity to ask questions. If families expressed an interest in participating, informed consent and child assent were obtained. After giving consent and assent, participating families completed study questionnaires: seven for caregivers, and three for youth. In order to expedite the time families spent in clinic and cause minimal disruption to clinic flow, families were approached prior to seeing the physician, and typically completed their study measures both before and after the clinic visit. Research team members gave instructions to caregivers and youth regarding how to complete each study measure, and assisted them in completing the first few items. If any participant demonstrated difficulty with reading or writing, research staff provided assistance (i.e., reading items aloud, marking answers in the correct spaces).

Researchers also conducted a medical chart review and retrieved downloaded adherence data from the participant's CPAP machine. After completing the study-related measures, participating families received a \$5 store gift card as compensation for their time. Families were sent an additional \$5 gift card if they completed and returned the ABCQ mailed to them two weeks after initial study participation.

In order to protect confidentiality of participants and data, all study measures were coded with a participant number that had no identifying connection to the participant. Signed consent and assent forms were stored in a locked cabinet separate from all other study forms and materials. Data files were stored in locked file cabinets within the

research laboratory of the principal investigator in the Department of Clinical and Health Psychology at the University of Florida.

Measures

Patient Information Form. This caregiver-completed form was designed for the purpose of this study to gather relevant demographic information, such as: child and parent age, gender, race, parent marital status, family income and parent education. A brief set of questions to assess parent and child medical history also was included. Responses were used to provide descriptive data for our sample and to code potential covariates in statistical analyses.

Adherence Barriers to CPAP Questionnaire (ABCQ). The primary measure of interest, the ABCQ was developed specifically for the purpose of this study to assess child and family barriers to adherence to the CPAP treatment regimen. Separate child- and caregiver-versions included items across a number of conceptually-derived domains, including: side effects, time/forgetfulness & daily hassle, attitudes & beliefs, healthcare provider relationships, psychological & behavioral concerns, social & family support, and equipment problems & environmental factors. Based on a comprehensive review of the literature, approximately 50 potential items were generated across these domains. The measure underwent careful review by physicians, nurses, pediatric psychologists, and psychology graduate students, all with experience working with children with chronic illness. Based on their feedback, the measure was culled to 31 items. The Flesch-Kincaid readability scale (Kincaid, Fishburne, Rogers, & Chissom, 1975) was used to determine a grade reading level of 2.7 and 3.2 for the youth and caregiver versions respectively, making it appropriate for the age-range of the study.

Using this list of items, the ABCQ was pilot-tested with a group of 5 youth and their caregivers from the Pediatric Pulmonary Clinic who met the study's inclusion and exclusion criteria. They were asked to complete the measure and provide their opinions regarding the clarity and relevance of the items for subsequent modification of the measure. Overall, no concerns were raised regarding wording or item content. Based on participant feedback, the Likert-type scale was changed from frequency of occurrence to strength of agreement for each item to reduce confusion. No other barriers were identified for inclusion in the measure, and none of the existing items were selected for deletion.

Instructions normalized non-adherence and informed participants that the purpose of the measure is to “understand the things that make using CPAP hard for children and teens with Sleep Apnea.” Participants answered each item for strength of agreement over the previous two-week period using a five-point Likert-type scale rating: Strongly Disagree, Disagree, Neutral (neither disagree nor agree), Agree, or Strongly Agree. A Total Barriers Score was calculated using the sum of all item responses. Higher scores indicate more barriers. See Appendix A for a copy of the measure.

Children's Sleep Habits Questionnaire (CSHQ; Owens, Spirito, & McGuinn, 2000). The CHSQ assesses sleep behaviors via caregiver report over a typical week for a variety of sleep domains. While the measure was originally intended for use with children age four to ten, it also has been utilized with children through age 18 years (e.g., Beebe et al., 2007; Hart, Palermo, & Rosen, 2005). For the purpose of this study, three subscale scores were used to determine caregiver's perceptions of their child's OSA severity: Sleep Disordered Breathing, Sleep Duration, and Daytime Sleepiness (14

items). Example items from these subscales include, “child snores loudly,” “child sleeps too little,” and “child seems tired,” respectively. Caregivers rate the frequency for each item based on a three-point scale: Usually (5-7 times per week), Sometimes (2-4 times per week), or Rarely (0-1 times per week). Items are totaled to obtain subscale scores such that higher scores indicate more sleep problems. The measure has been shown to adequately differentiate between a clinical and community sample and has demonstrated acceptable internal consistency ($\alpha = 0.78$), and test-retest reliability (0.62-0.79) in a sleep clinic sample (Owens et al.). Internal consistency for the current sample was excellent (Cronbach’s $\alpha = 0.86$).

School Sleep Habits Survey (SSHS; Acebo & Carskadon, 2002). This self-report measure examines sleep and wake behaviors in youth. Two subscale scores were used in analyses to assess youth perceptions of their disease severity: Sleepiness and Sleep/Wake Problem Behavior. Example items from these subscales include: “In the last two weeks, how often have you felt tired, dragged out, or sleepy during the day?”, “When you wake up in the morning, how long does it take for you to be totally ‘with it’?”, and “During the last two weeks, have you struggled to stay awake (fought sleep) or fallen asleep during studying?” The SSHS has been used widely in the sleep literature with pre-adolescent and adolescent populations, and has been found to correlate highly with both sleep-diary report and actigraphy data (Wolfson et al., 2002). Internal consistency of the measure for the study sample was high (Cronbach’s $\alpha = 0.84$).

Beliefs About Medicine Scale (BAMS; Riekert & Drotar, 2002). The BAMS assesses health beliefs about medical treatment for youth and caregivers. The original

measure was created for patients with a variety of diagnoses prescribed oral medications, but was adapted for this study for youth prescribed CPAP. The measure consists of 59-items on a 7-point Likert-type scale, and items were derived from constructs related to the Health Belief Model and other theories of health beliefs. In order to gain information on components of the Health Belief Model, analyses in the current study examined the Perceived Threat (i.e., perceived susceptibility), Positive Outcome Expectancy, and Negative Outcome Expectancy (i.e., perceived benefit) subscales. Subscales were supported by confirmatory factor analysis, and the BAMS has demonstrated excellent internal consistency ($\alpha = 0.79 - 0.87$) and test-retest reliability ($0.71 - 0.77$) in a sample of youth with HIV, Inflammatory Bowel Disease, and asthma (Riekert & Drotar, 2002). The measure has also been adapted for use with caregivers of youth with Sickle Cell Disease (Witherspoon & Drotar, 2006). The measure as adapted for caregivers and youth with OSA maintained adequate internal consistency for both caregivers (Cronbach's $\alpha = 0.74$) and youth (Cronbach's $\alpha = 0.85$) in the current study.

Behavior Assessment System for Children, Second Edition, Parent Rating Scales (BASC-2: PRS; Reynolds & Kamphaus, 2004). The BASC-2: PRS assessed parent ratings of youth behavior problems in the home and community environment. Two forms exist for the age range of this study: one for youth age 6-11 and one for older children 12-21. Parents rated the frequency of each behavior on a 4-point from "never" to "almost always." Total raw scores were converted into scaled scores based on age- and gender-based normative data. The measure consists of a variety of scales, but the current study examined only the Externalizing Problems and Internalizing Problems

Composite Scales. The measure has well-established norms based on a large general sample of youth from a variety of settings in the U.S., as well as a clinical sample of children with various emotional, behavioral, and physical diagnoses (Reynolds & Kamphaus). The measure demonstrated high reliability and strong correlations with other behavioral assessment measures (Reynolds & Kamphaus). Internal consistency for the current sample ranged from 0.90 to 0.92.

Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983). The FAD is a 60-item parent-report questionnaire of family functioning. Caregivers rated each item, such as “We avoid discussing our fears and concerns”, and “We often don’t say what we mean”, on a 4-point Likert-type scale from 1 (strongly agree) to 4 (strongly disagree). The measure contains six subscales and an overall general functioning scale score. The FAD questionnaire has demonstrated adequate reliability and validity (Miller, Epstein, Bishop, & Keitner, 1985), and has been used to study family functioning in other pediatric chronic illness populations such as asthma (e.g., Fiese & Wamboldt, 2003) and diabetes (e.g., Leonard, Jang, Savik & Plumbo, 2005). For the purpose of the current study, families completed only the General Functioning scale. This is consistent with previous studies that use only this subscale (i.e., Georgiades, Boyle, Jenkins, Sanford, & Lipman, 2008), and with the recommendation of Ridenour and colleagues (1999) based on a factor analysis of the FAD revealing that the General Functioning scale provides the best summary of family functioning. For the current study sample, internal consistency of this subscale was high (Cronbach’s alpha = 0.88).

PedsQL Healthcare Satisfaction Generic Module (Varni et al., 2004). This measure assessed parent satisfaction with their child’s healthcare over six domains:

Information, Inclusion of Family, Communication, Technical Skills, Emotional Needs, and Overall Satisfaction. Only the Overall Satisfaction domain was used in analyses. Respondents rated how content they were for each of 24 items using a 5-point Likert-scale ranging from 0 (never satisfied) to 4 (always satisfied). Scale scores were calculated using the sum of the items divided by the number of items answered, to account for missing data, and scores were transformed to a 0-100 scale (0 = 0, 1 = 25, 2 = 50, 3 = 75, 4 = 100), with higher scores indicating greater healthcare satisfaction. The PedsQL Healthcare Satisfaction Generic Module was adapted for general use from the original module designed for the hematology/oncology population, which has demonstrated excellent psychometric properties, including high internal consistency (Cronbach's alpha = 0.96) (Varni, Quiggins, & Ayala, 2000). Similar findings were seen using the current population (Cronbach's alpha = 0.98).

Adherence to CPAP. Data from participant's CPAP machines was culled via electronic download to provide information on adherence to treatment. Electronic monitoring is considered the "gold standard" of adherence measurement, and provides the advantage of assessing continuous, long-term adherence as it occurs (Quittner, Modi, Lemanek, Ievers-Landis, & Rapoff, 2008). Electronic monitoring has been routinely used in pediatric OSA research (e.g., Weaver, 2006; Uong et al., 2007).

Patient usage information is obtained approximately every three months as current standard of care practice for patients in our clinic. For the purpose of this study, data from the most recent previous three month period from the participant's study visit were examined. Patients in the Pulmonary Clinic have a variety of CPAP devices, but generally adherence data were stored on a computer chip in the machine and

downloaded using special computer software, which generates specific usage information. For the Resperonics CPAP machines, of which a majority of patients in our clinic use, usage information is stored on a SmartCard in the machine and is uploaded onto a computer using a USB reader into the EncorePro computer program (Phillips Resperonics, 2008). This program generates graphical displays of hours of daily usage, level of daily pressure, and daily patterns of use (i.e., time of day used). See Appendix B for a sample report from the EncorePro software. The program also calculates Compliance Statistics and Sleep Therapy Statistics. For the purpose of this study, average daily usage (all days in monitoring period) served as the primary measure for analyses.

Medical Chart Review. A member of the research team reviewed the patient's medical chart to obtain polysomnography (PSG) results, and the patient's prescribed treatment plan.

Polysomnography. Results from participants' routine diagnostic PSG were obtained from their medical chart. PSG is a diagnostic method that quantifies the respiratory abnormalities found in OSA, and is considered the gold standard (Section on Pediatric Pulmonology, 2002). The sleep study is an inpatient, overnight procedure that takes place in a pediatric facility at approximately the child's typical bedtime without sedation or sleep deprivation in order to closely replicate normal sleep. A variety of monitoring devices are used to obtain information on a number of variables. Sleep stages are evaluated using electroencephalogram (EEG), electromyogram (EMG), and electro-oculogram (EOG); chest and abdominal belts are used to gauge respiratory effort; air entry is assessed with a thermistor, nasal pressure, and a capnograph tracing;

extremity movements are monitored; a snore microphone placed on the neck records snoring; and gas exchange is evaluated (Wagner & Torrez, 2007). A range of information is obtained, and is reviewed and scored by an experienced technician, and interpreted by the supervising sleep medicine physician. Variables of interest for the current study include: the number of nighttime arousals, the presence or absence of snoring, and respiratory events. Respiratory events include apneas (a complete cessation of airflow) and hypopneas (a partial cessation of airflow). The apnea-hypopnea index (AHI) is calculated by dividing the number of apneic and hypopneic events by the total hours of sleep. Based on the AHI, children were classified according to the severity of their OSA. An AHI of 1-4 is considered mild, 5-10 is moderate, and 11 or more is severe (Mindell & Owens, 2003).

Statistical Analyses

All data analyses were conducted through use of Statistical Package for the Social Sciences 15.0 (SPSS). Descriptive information for the sample are given, and means and standard deviations are presented for CPAP adherence data. Psychometric properties of the ABCQ were examined utilizing Cronbach's alpha, and Pearson and Spearman correlations. Models examining psychosocial functioning and the Health Belief Model utilized multiple regression analyses.

Data were examined to determine skewness (the extent to which the distribution deviates from symmetry around the mean) and kurtosis (the peakedness or flatness of the distribution) of the sample for the variables of interest. Normality assumptions were considered met if the z-scores for skewness and kurtosis were within +/- 1.96. If assumptions were violated, non-parametric tests were performed.

CHAPTER 3 RESULTS

Sample Descriptive Data

The mean age of the 51 children who completed the study was 13.26 years ($SD = 2.45$), of which 51% were male. Fifty-one percent identified themselves as Caucasian, 37% as African American, and an additional 12% identified as from other racial or ethnic backgrounds. Caregivers were primarily mothers (70%) with a mean age of 41.27 ($SD = 9.76$), and 44% were from two-parent households. The sample was primarily of low socioeconomic status (median annual income level of \$20k-30k).

The health status of patients in this study varied substantially, but youth on average had severe OSA (AHI $M = 16.68$, $SD = 21.47$). Approximately 73.5% of the sample was classified as either overweight or obese (BMI at or above the 85% percentile for age and gender). Caregivers reported that 68% of youth had been diagnosed with either ADHD or a Learning Disability, which have been shown to be more common in youth with OSA.

Aim 1 - CPAP Adherence

For Hypothesis 1, descriptive statistics regarding youth adherence over the previous three months, including mean and standard deviation, are presented.

Information on the type of CPAP device and manufacturer, mask-type, and home healthcare provider are described in Table 3-1. One-way ANOVA and independent sample t-tests analyses were performed to determine if there were any differences in adherence by equipment type. No differences were found by device type ($F[4, 43] = .69$, $p = .60$), device brand ($F[2, 44] = 1.09$, $p = .35$), mask type ($t[46] = .45$, $p = .66$) or home health care provider ($F[3, 43] = 2.34$, $p = .09$). Patients in the study had been prescribed

CPAP for an average of 22.91 months ($SD = 18.25$; Range = 6 - 94). Adherence downloads were obtained for the most recent period available prior to their clinic appointment (Range of duration of adherence data = 1 – 394 days, Median = 59 days). Overall, adherence generally was poor. Across all days in the monitoring period, youth used their CPAP for an average of 3.35 hours per night ($SD = 2.79$). Considering only the days in which the CPAP was used, average use was 5.01 hours per night ($SD = 2.51$). Youth used CPAP for at least 4 hours per night on an average of 44% of days monitored ($SD = 44.81$). See Table 3-2 for additional adherence information.

Aim 2 - Psychometric Properties of the ABCQ

For Hypothesis 2.1, that the ABCQ will demonstrate adequate internal consistency, a Cronbach's alpha coefficient was calculated (Cronbach, 1951). This analysis evaluates the homogeneity of the test items and the extent to which items correspond to the same construct. An alpha level of .70 or greater is considered adequate (Kline, 1986). Results demonstrated good internal consistency, youth $\alpha = .89$ and caregiver $\alpha = .90$. Item-total correlations were above .3 for all but 4 of the items for youth and 2 items for caregivers, indicating most items are consistent with the rest of the measure. Deleting these items would not increase Cronbach's alpha by a significant amount (up to .006 for youth and up to .004 for caregivers).

For Hypothesis 2.2, to determine whether participant responses on the ABCQ remain consistent upon retest, Pearson product-moment correlations were used to examine the degree of association between ABCQ scores at initial testing and 2-week post-test. Correlations above .60 are considered acceptable (Kline, 1986). Paired t -tests were performed to evaluate whether there is a statistically significant change in scores

from initial testing to 2-week post-test. A third (31.3%) of the sample returned the questionnaire mailed to them two-weeks after their initial assessment. Correlations revealed excellent test-retest reliability for the baseline and 2-week assessment of the ABCQ, with correlations of .81 and .73 ($p = .001$) for youth and caregiver respectively. Additionally, the paired t -test showed participants reported change in number of barriers across time was not significant, $t(14) = .95, p = .36$ (youth), $t(15) = .74, p = .47$ (caregivers).

For Hypothesis 2.3, to assess validity, correlations were conducted between the ABCQ total score and each variable of interest. Specifically, Pearson product-moment correlations were run for normal variables (CPAP adherence), while Spearman correlations were utilized for non-normal variables (health-care satisfaction and negative outcome expectancy). If the ABCQ scores corresponded to the variables in the direction hypothesized (e.g., more barriers associated with poorer adherence, less health-care satisfaction, and greater negative outcome expectancy), based on information regarding known barriers to adherence and the OSA population, the measure is considered to demonstrate convergent validity (Kline, 1986). Indeed, the measure did demonstrate adequate convergent validity. Greater barriers to adherence also was associated with poorer rates of adherence (mean daily usage for all days) for both caregiver ($r = -0.44, p = .002, N = 48$) and youth ($r = -0.44, p = .002, N = 48$). Greater barriers to adherence was also associated with lower ratings of health-care satisfaction for caregiver ($r = -0.32, p = .02, N = 51$) and youth ($r = -0.68, p = .001, N=51$). Finally, more barriers to adherence was associated with greater negative outcome expectancy as measured with the BAMS (caregiver: $r = 0.64, p = .001, N = 51$ and youth: $r = 0.40, p = .004, N=51$).

Both youth and caregivers endorsed a moderate number and diverse range of barriers (Youth: $M = 70.98$, $SD = 17.72$; Caregivers: $M = 60.89$, $SD = 16.54$; maximum possible = 155). The most frequently endorsed barriers to CPAP were similar for caregivers and their children (Table 3-3). These barriers can be classified into several categories: Side Effects (not using CPAP when child does not feel well), Time, Forgetfulness & Daily Hassle (forgetting; not using CPAP when away from home), Psychological & Behavioral Concerns (child does not feel like using CPAP; child embarrassed about using CPAP; desire to forget about having OSA), and Social & Family Support (no one available to help use CPAP at night).

Aim 3 - Psychosocial Functioning

The majority of youth were in the non-clinical range for BASC-2:PRS scores, with fewer children falling in the at-risk or clinically significant ranges (Table 3-4). Of note, over a quarter of the sample endorsed at risk or clinically significant levels of anxiety, and nearly 40% had at risk or clinically significant levels of depression. With respect to family functioning, scores indicated an average of healthy family functioning ($M = 1.60$, $SD = 0.45$; clinical cut-off = 2.0); however, a third of the sample endorsed clinically problematic functioning for the General Functioning subscale.

For Hypothesis 3, Pearson product-moment and point-biserial correlations (for continuous and dichotomous variables, respectively) were performed between adherence and demographic variables to identify variables to control for in subsequent analyses. No significant correlations were found for age, gender, race/ethnicity, BMI percentile, AHI, or pressure levels; thus, no control variables were used.

A multiple regression analysis was conducted using the FAD General Functioning Scale score, and BASC-2:PRS Internalizing and Externalizing Composite Scores to

identify variables that contributed significant variance explained in association with adherence. The overall model did not reach significance, $F(3, 44) = 0.081, p = .970$ (Table 3-5).

Aim 4 - Health Beliefs

Descriptive data for the health belief variables are illustrated in Table 3-6. For Hypothesis 4, two multiple regression analyses (one for caregiver beliefs and another for youth beliefs) were conducted with adherence as an independent variable and health beliefs entered as dependent variables. Variables included in the Health Belief model included: perceived disease severity (based on caregiver-rated Child Sleep Habits Questionnaire (CSHQ) scores and youth School Sleep Habits Survey (SSHS) scores), perceived susceptibility ratings and ratings of perceived benefit of treatment acquired from the BAMS, and Total Barriers scores from the caregiver and youth versions of the ABCQ. No control variables were entered, given the lack of significant association for demographic variables.

The final model for both caregivers, $F(4, 44) = 3.50, p = .014$, and youth, $F(4, 44) = 2.97, p = .03$ reached significance (Table 3-7). However, none of the variables contributed significant variance to the model, though Total Barriers trended towards significance, such that for every additional barrier reported, there was a corresponding decrease in CPAP usage of approximately 3.5 minutes.

Assumptions were examined for the model, revealing no collinearity within the data, independent residuals in the model, and that assumptions of normality and linearity were met. Thus, the model appears to be accurate for the sample.

Table 3-1. CPAP information

		Percentage of Sample
Device type	CPAP	45.8%
	BiPAP	6.3%
	AutoPAP	47.9%
Device manufacturer	Resperonics	75.0%
	ResMed	10.4%
	Other	14.6%
Mask type	Full-face	85.7%
	Nasal only	14.3%
Home healthcare provider	Pediatric Health Choice	76.0%
	Barnes Option Care	14.0%
	Apria	4.0%
	DESLOGE Home	4.0%
	Home Respiratory Solutions	2.0%

Table 3-2. CPAP utilization

	N	Min.	Max.	Mean	SD
Apnea-Hypopnea Index	50	0.2	83.8	16.7	21.5
Months prescribed CPAP	46	6.0	94.0	22.9	18.2
Mean daily CPAP usage -all days monitored (min.)*	48	7.0	563.0	201.3	167.7
Mean daily CPAP usage -only days used (min.)*	47	19.0	583.0	300.9	151.0
Mean CPAP pressure*	41	2.0	24.0	8.9	4.0
Time in leak (min.)*	32	0.0	83.0	15.9	18.9
% days used \geq 4hrs*	48	0.0	240.0	44.0	44.8

Note: Apnea-Hypopnea Index: 1-4 = mild; 5-10 = moderate, 11+ = severe.

*Information obtained from CPAP device download of electronic monitoring data.

Table 3-3. Most frequently endorsed barriers to CPAP reported on the ABCQ

<u>Caregiver- Report</u>		<u>Youth-Report</u>	
Item		Item	
Does not use when away from home	45.1%	Does not use when away from home	47.0%
Child not feeling well	44.0%	Just want to forget about OSA	43.1%
Forgets	39.2%	Not feeling well	42.0%
Child does not feel like using CPAP	30.0%	Forgets	39.2%
Child just wants to forget about OSA	23.6%	No one helps to use CPAP at night	31.4%
Child embarrassed about using CPAP	22.0%	Embarrassed about using CPAP	29.4%

Note: Indicates percentage of sample endorsing "Agree" or "Strongly Agree"; ABCQ = Adherence Barriers to CPAP Questionnaire.

Table 3-4. Participants in each category on the *BASC-2:PRS*

	Nonclinical	At risk	Clinically significant
Hyperactivity	76.5%	17.6%	5.9%
Aggression	80.4%	13.7%	5.9%
Conduct	84.0%	10.0%	6.0%
Externalizing Composite	80.0%	12.0%	8.0%
Anxiety	72.5%	13.7%	13.7%
Depression	60.8%	19.6%	19.6%
Somatization	58.8%	29.4%	11.8%
Internalizing Composite	54.9%	27.5%	17.6%

Note: Nonclinical T-score < 59; at risk T-score 60-69; clinically significant T-score > 70.
 BASC-2:PRS = Behavior Assessment System for Children, 2nd Ed., Parent Rating Scales

Table 3-5. Regression model for psychosocial functioning and CPAP adherence

	<i>B</i>	<i>SE B</i>	β	<i>p</i>
Constant	201.77	157.16		
Family Functioning ^a	29.95	57.51	.07	.64
Internalizing Problems ^b	0.07	2.38	.01	.98
Externalizing Problems ^b	-0.87	3.20	-.05	.79

Note: $R^2 = .005$ for Model.

^aFamily Assessment Device.

^bBehavior Assessment System for Children, 2nd Ed., Parent Rating Scales.

Table 3-6. Descriptive data for health belief variables

	Mean	SD	Max. Possible
Illness susceptibility			
BAMS - Caregiver	39.45	12.23	91
BAMS - Youth	37.18	13.53	91
Perceived benefits			
BAMS - Caregiver	108.61	17.03	140
BAMS - Youth	97.02	19.91	140
Perceived disease severity			
CSHQ – Caregiver	4.84	1.92	9
SSHS - Youth	16.71	6.93	24

Note: BAMS = Beliefs About Medicine Scale; CSHQ = Children’s Sleep Habits Questionnaire; SSHS = School Sleep Habits Survey

Table 3-7. Regression model for health beliefs and CPAP adherence.

	<i>B</i>	<i>SE B</i>	β	<i>p</i>
Caregiver model				
Constant	570.90	240.96		
Illness susceptibility	-2.29	2.16	-.17	.29
Perceived benefits	0.11	1.53	.01	.94
Barriers	-3.72	1.92	-.35	.06
Perceived disease severity	-14.32	11.49	-.17	.22
Youth model				
Constant	531.81	205.34		
Illness susceptibility	-1.79	2.02	-.14	.38
Perceived benefits	0.07	1.42	.01	.96
Barriers	-3.37	1.78	-.35	.06
Perceived disease severity	-1.84	3.25	-.08	.57

Note: $R^2 = .24$ for caregiver model; $R^2 = .21$ for youth model.

CHAPTER 4 DISCUSSION

Obstructive Sleep Apnea is increasingly prevalent in children and adolescents and can affect both daytime and nighttime functioning (Meltzer & Mindell, 2006; Mindell & Owens, 2003). Because of the potential serious negative consequences (e.g., cardiovascular morbidity, cognitive and behavioral problems) of the disease, consistent management with nightly use of a CPAP device is imperative. Similar to other chronic illness treatment regimens, adherence to CPAP has been documented to be poor in adults (DiMatteo, Giordani, Lepper, & Croghan, 2002; Kyngas, Kroll, & Duffy, 2000; Olsen, Smith & Oei, 2008). Yet, a mere three studies have examined CPAP adherence in youth with OSA. In addition to a paucity of studies documenting rates of adherence, the variables that may account for non-adherence are unknown. Knowledge of specific barriers and other correlates to adherence is vital to inform interventions; yet, no measures exist to obtain this information from families and children with OSA. The current study builds upon previous work in the extant literature by describing patterns of adherence in youth with OSA, developing a measure of barriers to adherence, and examining correlates to adherence to the CPAP treatment regimen.

CPAP Adherence

Overall adherence for youth in the current study was poor, which is consistent with previously reported adherence for children with OSA. This is particularly worrisome, given the severe disease status of the study sample. Across the three extant studies examining CPAP adherence (Marcus et al. 2006; O'Donnell, Bjornson, Bohn & Kirk, 2006; Uong, Epperson, Bathon & Jeffe, 2007), usage ranged from 4.7 to 7 hours per night, and most children did not use their CPAP every night as prescribed. These rates

are somewhat higher than youth in the current study, where average nightly usage was 3.35 hours for all nights in the monitoring period. The reasons for higher rates in the previous studies may be due to the nature of those studies: one study (Marcus et al.) followed children newly prescribed CPAP for their first 6 months of use when adherence may be higher due to novel aspects of treatment, while the current study required youth to have been prescribed CPAP for at least 6 months in order to participate. Similarly, another study (Uong, Epperson, Bathon & Jeffe) examined children after participation in an intervention program that provided newly prescribed CPAP patients with comprehensive education and follow-up that may have influenced adherence rates, while children in the current study received standard clinic care. Despite these differences, it is clear that youth are not using their CPAP every night, for the entire night's duration as prescribed.

One limitation of the current study, and indeed, the entire extant CPAP adherence literature, is the non-standardized and inadequate definition of adherence. For example, one study cited usage as a minimum of one hour per night (O'Donnell, Bjornson, Bohn & Kirk, 2006), while another considered non-adherence as less than 3 hours of use per night (Marcus et al., 2006). Finally, the third study used more stringent criteria for adherence of greater than four hours per night for five or more nights per week (Uong, Epperson, Bathon & Jeffe, 2007). The current study did not utilize a cut-off for adherence, but rather chose to use adherence as a continuous variable, to take into account the variability in usage among patients. Additional information obtained by the CPAP adherence download include: average use only for days when CPAP was used, percent days used for four or more hours per night, pressure levels, and time in leak.

However, these numbers still do not fully capture the extent to which children are using their CPAP. One innovative study by Aloia and colleagues (2008) used time series analysis to determine patterns of adherence in adults using CPAP. They classified participants into categories such as “Good Users,” “Slow Decliners,” and “Occasional Attempters.” The authors argue that traditional examinations of adherence utilizing only sample means results in a masking of important information. The advantage of time series analysis is the ability to take into account individual differences. It would be valuable to utilize time series analysis in a pediatric OSA sample in order to discover specific patterns of adherence as well as variables that predict different patterns of use that may be unique to this population.

Barriers to Adherence

The Adherence Barriers to CPAP Questionnaire demonstrated excellent psychometric properties, including internal consistency, test-retest reliability, and convergent validity. This measure is the first to examine child- and parent-reported barriers to adherence to the CPAP regimen. As predicted, both caregivers and youth endorsed many barriers across a diverse range to following the CPAP regimen. This finding is similar to previous studies examining barriers to chronic illness. For example, Modi and Quittner (2006) found that over 70% of parents and children with Cystic Fibrosis and asthma endorsed barriers to adherence to their respective treatment regimens. The ABCQ is a brief tool that could be easily administered and scored in a medical clinic by healthcare personnel to determine those obstacles to adherence most salient to families. After identifying these barriers, the medical team can work with families on the issues important to them to improve future adherence (e.g., through family-centered problem solving). Further study is needed to determine the

effectiveness of using the measure as a screening tool and as a measure of treatment outcome for intervention efforts in a clinic setting.

Significantly, both parents and youth are endorsing psychosocial barriers, such as embarrassment about having to use CPAP and a desire to forget about their OSA diagnosis. Especially in the pre-adolescent and teenage years, youth are particularly susceptible to peer pressure and strive to appear “normal.” Using the CPAP device could act as a reminder that they are different from their peers. Thus, non-adherence could be a way of obtaining social acceptance, despite the negative health consequences. Indeed, this is not unique to youth with OSA: Simons and Blount (2007) solicited barriers to adherence for youth receiving organ transplants and found similar endorsement of common “adolescent issues,” for example, “tired of taking medications.” Given that youth with chronic illness are a greater risk for psychological problems than healthy peers (Blackman & Gurka, 2007; Quittner et al., 2008), providing appropriate intervention when youth report these psychosocial concerns may be a beneficial preventative measure.

While beyond the scope of the current study, an interesting future direction would be to examine differences between parent- and child-report of barriers to adherence. If caregivers are not aware of the barriers their children are experiencing, they may be unable to help them work towards improving adherence. Or, if parents and youth are endorsing similar barriers, it may be that families lack the knowledge or skills to improve adherence, and could benefit from outside intervention from a medical or mental health practitioner. Interventions to assist parents and youth in learning and implementing strategies to improve adherence could be beneficial for improved health outcomes.

Psychosocial Correlates

Youth in the study had on average nonclinical levels of behavior problems, though over a third of the sample had at-risk or clinically significant levels of anxiety or depression as measured by the BASC. This percentage of children in the at-risk or clinically significant range is noticeably larger than that from a group of healthy control children drawn from the normative sample, and is comparable to a group of youth with cancer (Wolfe-Christensen, Mullins, Stinnet, Carpentier & Fedele, 2009). Indeed, a meta-analysis of the extant literature shows parents of children with OSA are more likely to report that their child experiences internalizing and externalizing behavior problems than parents of healthy children (Mitchell & Kelly, 2006). Similarly, adults with OSA are more likely to endorse clinically significant symptoms of depression and anxiety, regardless of disease severity (Macey, Woo, Kumar, Cross & Harper, 2010). These findings implicate the importance of increasing awareness of the risk for psychological distress in youth with OSA in both parents and healthcare providers. A routine screening during clinic appointments could easily identify patients in need of either brief intervention in clinic or referral to an appropriate clinician.

Contrary to hypotheses, the proposed model examining adherence and psychosocial variables did not reach significance. This may be due to a number of limiting factors, such as the average normative functioning of youth in the study. However, over a third of youth had clinically significant behavior difficulties, and a third of the sample endorsed poor family functioning. Thus, it is possible that, despite these difficulties, psychosocial variables are not as important as other variables such as barriers in predicting adherence. Nonetheless, further study utilizing a larger sample would allow for analyses to examine differences in CPAP adherence between youth and

families with healthy functioning and those with more significant problems in psychosocial outcomes.

Health Beliefs

Current analyses supported the assumption that health beliefs would significantly account for a portion of the variance in adherence. In fact, the model accounted for 21% and 24% of variance for youth and caregivers, respectively, with barriers being the primary contributor to the model (though this variable did not reach significance). These results correspond to a similar study of health beliefs in youth with a variety of other chronic illnesses (HIV, asthma, and Inflammatory Bowel Disease), where negative outcome expectancy and intent to adhere to treatment were significant contributors to the health belief model (Reikert & Drotar, 2002). While no previous studies have examined health beliefs in youth with OSA, interesting findings have been found with adults. In a quantitative study of 15 adults with OSA, researchers found specific patterns for adherent and non-adherent patients: adherent patients accurately perceived the risks of OSA, had definite expectations for treatment, and endorsed fewer barriers, while non-adherent patients were unaware of risks, endorsed fewer symptoms of OSA, perceived less improvement upon treatment, and cited more barriers (Sawyer, Deatrck, Kuna, & Weaver, 2010). Sage and colleagues (2001) found that patient self-efficacy and barriers to treatment were moderately correlated with CPAP adherence. Contrary to the current study, they also found that perceived benefit of treatment was also associated with adherence. Finally, in a sample of 122 adults with OSA, patients with maladaptive beliefs regarding their illness and treatment had over twice as much risk of non-adherence in the month following treatment initiation (Pouler et al., 2009).

Patients' beliefs regarding their health, illness, and treatment clearly play a role in their treatment adherence. The nature of the present study (and indeed all extant research involving health beliefs in OSA) is correlational and thus no conclusions are able to be drawn regarding causality. For example, it is possible that adherent children and families observe greater improvement in symptoms due to consistent CPAP use and thus continue this pattern. In contrast, it may be that those who hold the belief that the CPAP treatment will improve their health subsequently adhere to their regimen. Further research is needed in order to tease out the causal nature of the relationships between health beliefs and adherence. Additionally, it is possible that these variables actually play a mediating or moderating role in predicting adherence.

Study Conclusions

This study highlights the importance of improving low adherence rates in children with OSA who have been prescribed a CPAP regimen. To date, no psychological interventions have been developed or examined for youth with OSA. With the technological advances in CPAP machine design, it is possible for healthcare practitioners to easily identify non-adherent youth via electronic download data. However, once they have this information, it is unclear how best to assist patients and families in improving adherence. It is important foremost to identify modifiable psychosocial predictors of adherence that can then be targeted in interventions. This study revealed that health beliefs are associated with CPAP adherence, particularly barriers to adherence. Use of the ABCQ as a screening device in the clinic setting is an easy and fast way to assess specific issues salient to patients. Inquiring about a family's beliefs regarding their illness and treatment could illuminate concerns or issues that can then be addressed. While psychosocial factors were not found to be significantly

associated with adherence, a significant number of youth had elevated levels of anxiety and depressive symptoms. A brief mental health screener may alert practitioners to any mood or anxiety problems. Subsequently, brief behavioral or cognitive-behavioral strategies can be implemented in clinic or appropriate referrals can be made for follow-up care to those individuals with more serious or recalcitrant psychosocial concerns.

In adults with CPAP, several interventions have been investigated in the literature, including behavioral and cognitive-behavioral interventions, home support, and psychoeducation (Olsen, 2008). While education-based interventions may increase patients' self-efficacy and help them develop positive beliefs regarding the effectiveness of CPAP treatment, these interventions have not consistently demonstrated efficacy in improving adherence (Olsen, 2008). Cognitive-behavioral interventions have shown to be more effective: one study demonstrated that those receiving a CBT treatment subsequently used their CPAP for 2.9-3.2 hours longer than a control group (Olsen, 2008). Components of this treatment included watching videos of other patients acting as positive role models and persevering through their treatment, learning relaxation strategies, and use of some motivational interviewing techniques. It is unclear whether any of these intervention techniques would be adaptable or beneficial to children and families, and thus is an area for future study.

While no intervention studies have been conducted on youth with OSA, lessons can be taken from the pediatric chronic illness literature at large. Two meta-analyses of adherence interventions for youth with chronic illness found that interventions that included a combination of behavioral and education components resulted in the greatest improvements in adherence and health outcomes (Graves, Roberts, Rapoff, & Boyer,

2010; Kahana, Drotar & Frazier, 2008). Components of these interventions included instruction specific to the illness and treatment, and applied behavioral strategies, such as problem solving and parent training. Given the results from these studies, which have primarily included youth with asthma, diabetes, and cystic fibrosis, it is conceivable that similar results may be found utilizing similar interventions tailored to the CPAP regimen for children with OSA. The literature emphasizes that a one-time intervention is unlikely to provide permanent changes, but rather adherence interventions should be conceptualized as a continuing part of ongoing clinical management of the illness (Kahana, Drotar & Frazier).

There are several limitations to the current study that deserve consideration. The study sample was a clinic-referred population; indeed, on average youth had severe OSA. Caregivers who attend a sleep-specialty clinic have specific concerns regarding their child's OSA and may not be representative of the general population of children receiving care through a pediatrician. Additionally, participants were recruited during their clinic appointment, during which adherence is typically discussed. Thus, social desirability may result in a tendency to report better than actual functioning. It is also necessary to consider the families that were unable to participate in the study due to their absence from clinic appointments. Indeed, our results may actually underestimate true levels of non-adherence given that families not attending clinic were not assessed. Additionally, families that are non-adherent to clinic attendance likely have high levels of non-adherence for other components of their medical regimen, and may have unique difficulties (e.g., barriers, psychosocial issues) that were unable to be assessed in the current study.

Because of the nature of the sleep clinic from which patients were recruited, it was not possible to standardize the duration of downloaded CPAP adherence information. While clinic standard-of-care is to obtain downloads for the previous three-month period, home health care aides were not always able to do so, given family availability or no-show or cancelled appointments. While the mean duration for adherence data was near the goal of three months ($M = 82.5$ days), the range was from 1 to 394 days. While not ideal, this is similar to other studies; for example, O'Donnell and colleagues (2006) had a download period that ranged from 8 to 979 days. Additionally, no published data were found regarding the reliability of objective data obtained from CPAP machines.

Despite these limitations, this study significantly adds to the extant literature by examining CPAP adherence, barriers and correlates in youth with OSA. Additional strengths of the study include utilizing multiple methods of assessment, having multiple informants and relying on an objective measure of adherence. Results of this study can be used to inform healthcare practitioners of the risk for non-adherence, and the potential for barriers to impact adherence in their patients. Additionally, the ABCQ appears to be a reliable and valid tool for clinicians to assess barriers to adherence; it also is easy to administer and score in a busy clinic setting. For researchers, this study offers targets for the development of adherence interventions specific to youth with OSA. While this study is an excellent foundation for enhancing our knowledge of barriers to adherence in youth with OSA, further research is imperative in order to better understand the difficulties children and families have with their CPAP regimen, as well as developing successful interventions in order to promote positive health outcomes.

APPENDIX A
ADHERENCE BARRIERS TO CPAP QUESTIONNAIRE

**Adherence Barriers to CPAP Questionnaire (ABCQ)
Patient Version**

There are no right or wrong answers to these questions. Your answers will be kept secret.

Most children and teens at one time or another have trouble with using CPAP for their Sleep Apnea.

We want to understand the things that make using CPAP hard for children and teens with Sleep Apnea.

These are some of the reasons other children and teens have said make it hard to use CPAP. We want to know how much each of these reasons have been true for you over the past two weeks.

Use this scale to answer each question:



1 Strongly Disagree	2 Disagree	3 Neutral (neither disagree nor agree)	4 Agree	5 Strongly Agree
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		Never	Rarely	Sometimes	Often	Very Often
1.	My CPAP makes my nose stuffed up (congested).					
2.	I forget to use my CPAP.					
3.	Using my CPAP is too much hassle.					
4.	I don't use my CPAP when I am not feeling well (e.g., cold, flu).					
5.	I don't feel like using my CPAP.					
6.	My doctors tell me to use my CPAP too much.					
7.	No one helps me use my CPAP at night.					
8.	My mask does not fit properly.					
9.	I feel embarrassed that I have to use my CPAP.					
10.	My CPAP makes me feel sick (e.g., headache, dry mouth, stomachache).					
11.	Using my CPAP gets in the way of doing what I want (e.g., friends, sports, school).					
12.	There is no place to keep my CPAP machine at home.					
13.	I don't understand why I have to use my CPAP.					
14.	I start out using my CPAP but have to stop it during the night.					
15.	I am worried my friends will find out about my Sleep Apnea.					
16.	My CPAP machine is often broken or doesn't work right.					
17.	I do not believe I can use my CPAP properly.					
18.	My doctors/nurses don't listen when I talk to them.					
19.	Using my CPAP does not make me feel better.					
20.	My facemask hurts or gives me a skin rash.					

		Never	Rarely	Sometimes	Often	Very Often
21.	I am too busy to use my CPAP.					
22.	I don't use my CPAP when I am away from home.					
23.	I can stay healthy without using my CPAP.					
24.	I don't understand how to use my CPAP.					
25.	I get worried or scared using my CPAP.					
26.	I fall asleep before I can put on my CPAP mask.					
27.	I think my CPAP machine and equipment costs too much money.					
28.	I can't sleep when I use my CPAP.					
29.	I can't use my CPAP every night, so I might as well not use it at all.					
30.	I just want to forget about my Sleep Apnea.					
31.	I am too tired at night to use my CPAP.					

Adherence Barriers to CPAP Questionnaire (ABCQ) Caregiver Version

There are no right or wrong answers to the questions in this survey. Your answers will be kept secret.

Most families at one time or another have trouble with using CPAP for their child's Sleep Apnea.

We want to understand the things that make using CPAP hard for families of children and teens with Sleep Apnea.

These are some of the reasons other families have said make it hard to use their children's CPAP. We want to know how much each of these reasons have been true for you and your child over the past two weeks.

Use this scale to answer each question:



1 Strongly Disagree	2 Disagree	3 Neutral (neither disagree nor agree)	4 Agree	5 Strongly Agree
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		Never	Rarely	Sometimes	Often	Very Often
1.	The CPAP makes my child's nose stuffed up (congested).					
2.	My child forgets to use their CPAP.					
3.	It is too much hassle to get my child to use their CPAP.					
4.	My child doesn't use CPAP when they are not feeling well (e.g., cold, flu).					
5.	My child doesn't feel like using their CPAP.					
6.	My child's doctors tell them to use their CPAP too much.					
7.	No one is able to help my child use their CPAP at night.					
8.	My child's mask does not fit properly.					
9.	My child is embarrassed that they have to use their CPAP.					
10.	The CPAP makes my child feel sick (e.g., headache, dry mouth, stomachache).					
11.	Using their CPAP gets in the way of my child doing other activities (e.g., friends, sports, school).					
12.	There is no place to keep my child's CPAP machine at home.					
13.	I don't understand why my child has to use their CPAP.					
14.	My child starts out using their CPAP but has to stop it during the night.					
15.	My child is worried their friends will find out about their Sleep Apnea.					
16.	My child's CPAP machine is often broken or doesn't work right.					
17.	I do not believe I can help my child use their CPAP properly.					
18.	My child's doctors/nurses don't listen when we talk to them.					
19.	Using CPAP does not make my child feel better.					

		Never	Rarely	Sometimes	Often	Very Often
20.	The facemask hurts or gives my child a skin rash.					
21.	My child is too busy to use their CPAP.					
22.	My child doesn't use their CPAP when they are away from home.					
23.	My child can stay healthy without using their CPAP.					
24.	I don't understand how to use my child's CPAP machine.					
25.	My child gets worried or scared using their CPAP.					
26.	My child falls asleep before they can put on their CPAP mask.					
27.	I think my child's CPAP machine and equipment costs too much money.					
28.	My child can't sleep when they use their CPAP.					
29.	My child can't use CPAP every night, so they might as well not use it at all.					
30.	My child just wants to forget about their Sleep Apnea.					
31.	We are too tired at night to use my child's CPAP.					

APPENDIX B
SAMPLE ELECTRONIC ADHERENCE DOWNLOAD REPORT



PROGRESS REPORT

**CPAP Patient
Physician's Copy**

*Center Based Care
Home Health Nursing
Pharmacy/Infusion Services
HME Services
Phototherapy
Case Management
Discharge Planning
Therapy: PT, OT, ST*

Date: 12/27/07

Patient Name: XXX XXX

Physician Name: PPC

CPAP / Auto-PAP / C Flex

Pressure: 13cm

C Flex: N/A

RAMP: X Yes No 45 Min.

O2 Liter Flow: room air

Nasal Application: *nasal gelmask. Also has a full face. Mom to tighten the straps. She stated she could sometimes hear it leaking.*

Compliance: X Yes No

491 blower hours but only 16 hours at therapeutic pressure.

Comments: Has a touch of bronchitis per mom. Waiting until spring for bypass surgery in Tampa. Large leak noted. Mom to check mask seal nightly.

we care for children



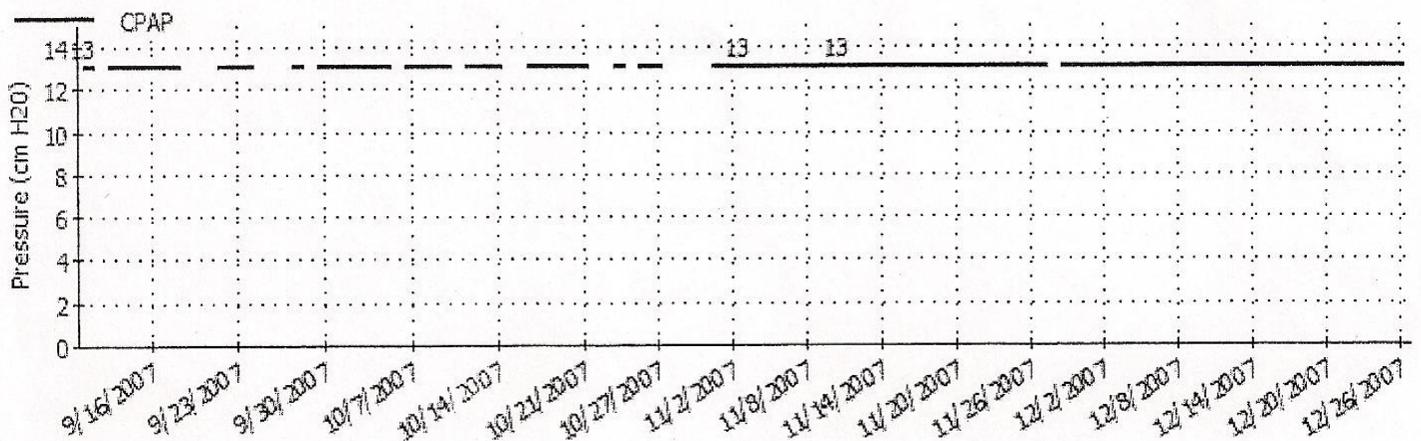
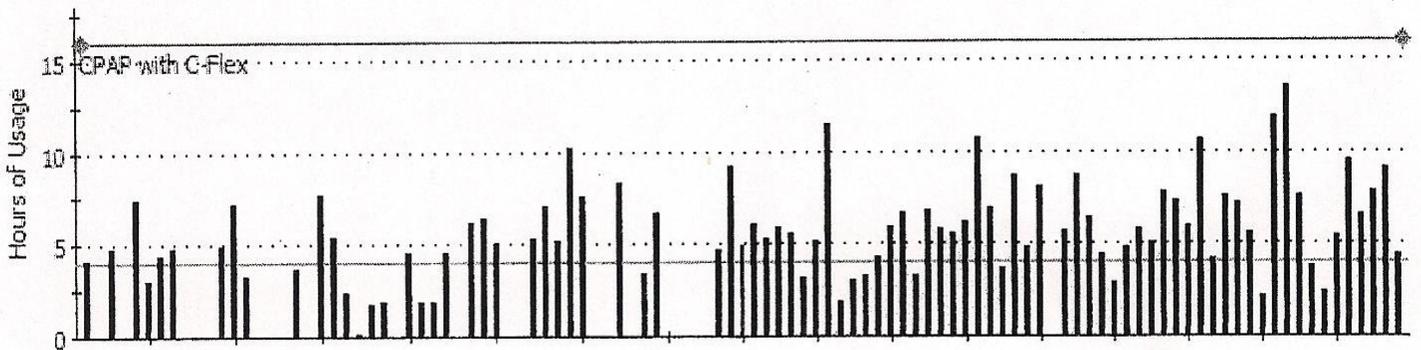
Patient: XXX XXX Patient ID XXXXX
Home Phone XXX-XXX-XXXX
Age XX

Referring Physician:

PCP:

Clinician:

Compliance Information 9/11/2007 – 12/26/2007



Summary of Compliance – All Data

Compliance Statistics

Date Range	9/11/2007 – 12/6/2007 (107 days)
Days with Device Usage	87 days
Days without Device Usage	20 days
Percent Days with Device Usage	81.3%
Cumulative Usage	16 hrs. 38 mins.
Maximum Usage (1 Day)	56 mins.
Average Usage (All Days)	9 mins.
Average Usage (Days Used)	11 mins.
Minimum Usage (1 Day)	2 mins.
Percent of Days with Usage >= 4 hours	0 %
Percent of Days with Usage < 4 hours	100%
Total Blower Hours (During Reported Period):	491 hrs. 8 mins.

Sleep Therapy Statistics

Average Time in Apnea Per Day	31.8 secs.
Average Time in Large Leak Per Day	0 mins.
Average AHI	13.5
CPAP Pressure	13.0 cm H2O

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BIOGRAPHICAL SKETCH

Stacey Lynn Simon grew up in Okemos, Michigan, and earned Bachelor of Arts degrees in music performance and psychology from Case Western Reserve University in 2005. She enrolled in the University of Florida's doctoral program in clinical psychology in 2006, where her primary area of study was pediatric psychology with a focus on medical regimen adherence. Stacey completed a predoctoral internship at Nationwide Children's Hospital, Columbus, Ohio, and received her Ph.D. from the University of Florida in the summer of 2011. She is currently pursuing a postdoctoral fellowship at Cincinnati Children's Hospital Medical Center in Cincinnati, Ohio.