



Parental understanding and attitudes of pediatric obstructive sleep apnea and adenotonsillectomy[☆]

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KEYWORDS

Obstructive sleep apnea;
Adenotonsillectomy;
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Summary

Objective: To explore parental perceptions and knowledge of pediatric obstructive sleep apnea (OSA) and adenotonsillectomy.

Design: Cross-sectional study.

Setting: National polling organization.

Participants: Population-based sample of 584 parents.

Intervention: Online surveys.

Main outcome measures: Responses to questions regarding knowledge of pediatric OSA and treatment with adenotonsillectomy.

Results: Ninety-five percent of parents acknowledged that pediatric OSA is a “serious condition”. Fifteen percent considered themselves to be “knowledgeable” about it. One fifth understood that untreated OSA could lead to cardiopulmonary disease, failure to thrive, or behavioral problems, such as attention deficit hyperactivity disorder. Less than 20% knew that pediatric OSA could be treated with adenotonsillectomy. Thirty-seven percent believed adenotonsillectomy to be an “outdated” procedure. Upon learning that adenotonsillectomy can treat OSA, 82% reported they would be eager to have a child with OSA undergo adenotonsillectomy.

Conclusions: The majority of parents do not understand symptoms, consequences and treatment of pediatric OSA secondary to adenotonsillar hypertrophy. Otolaryngologists should be diligent in communicating issues of this disorder with parents and pediatricians.

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1. Introduction

Obstructive sleep apnea and sleep disordered breathing are common problems encountered by pediatric otolaryngologists. A spectrum of severity of sleep-disordered breathing exists, ranging from the most mild, primary snoring, followed by upper airway resistance syndrome, to obstructive sleep apnea (OSA) [1]. Primary snoring is the most common presentation of sleep disordered breathing, with the incidence varying in the literature from 10 to 30% [2]. These children will not have an abnormal sleep study, but may suffer from the same sequelae of sleep disordered breathing as those children with more severe symptoms. Children with upper airway resistance syndrome will not have evidence of apnea on sleep study, but will have significant negative intrathoracic pressure during sleep on esophageal manometry. This condition is poorly documented and is likely more common than OSA. Obstructive sleep apnea syndrome is classified as periods of complete or partial alveolar hypoventilation with hypoxia. Current guidelines require a sleep study for diagnosis and although as few as one apneic event per hour is abnormal for children, most classify pediatric OSA as an apnea hypopnea index greater than five [2]. One to 3% of children have documented obstructive sleep apnea by sleep study [1,2].

Potential serious sequelae of obstructive sleep apnea, such as hypertension and right ventricular hypertrophy, as well as development of cardiac arrhythmias and cor pulmonale, have been reported in the literature [3,4]. Additionally, failure to thrive and metabolic or growth disturbances may also occur. Recently, attention has been placed on the behavioral and developmental impact of sleep disordered breathing. Although serious systemic sequelae are typically the result of severe obstructive sleep apnea, neurobehavioral effects of sleep-disordered breathing have been found in children with primary snoring [2]. Children are less likely to exhibit daytime fatigue from OSA than adults. Hyperactivity, aggression, behavioral problems, as well as poor attention are more commonly found in children with obstructive sleep apnea [5].

Unfortunately, many primary care physicians have a limited knowledge of the consequences of untreated pediatric obstructive sleep apnea. A survey conducted in 1990 by the National Council on Sleep Disorders Research found that 29% of medical schools offered little or no formal sleep education [6]. Since that time the National Institutes of Health has developed a task force for sleep research and education on sleep disorders. However a recent questionnaire given to parents demonstrated that

52% of pediatricians still did not inquire about sleep problems [7]. Owens surveyed 626 pediatricians regarding their knowledge of sleep disorders and sleep disordered breathing. The mean percentage of correct responses regarding knowledge of sleep disordered breathing was less than 50%, with less than 5% of clinicians answering all questions correctly. Few practitioners screen young children for sleep disorders and even fewer screen adolescents. The majority of inquiries made by pediatricians regarding sleep typically relate to bedtime and to sleep habits. Only 7.6% of pediatricians screen infants for snoring, 24% screen toddlers, 26.6% screen school-aged children, and 15.1% inquired about snoring in adolescents [8]. As a result of this lack of screening, many children with sleep-disordered breathing may go unrecognized. This was demonstrated after implementation of the "BEARS" (bedtime issues, excessive daytime sleepiness, night awakenings, regularity and snoring) sleep-screening tool in a pediatric residents' continuity clinic. BEARS is a screening instrument that Owens created to help pediatricians elicit information regarding sleep and identify sleep problems during routine clinic visits. Chart notes were significantly more likely to include information regarding sleep after utilizing the BEARS screening tool than prior to implementing BEARS. After the BEARS tool was included in the chart, 92.8% of visits had information regarding snoring as compared to 7.2% prior to its inclusion. 10.7% of patients were identified with snoring as compared to 4.6%, prior to the use of BEARS [9].

If pediatricians and other primary care physicians are not knowledgeable regarding obstructive sleep apnea and sleep disordered breathing, it can be inferred that the general population knows even less. With an unrestricted educational grant from ArthroCare Corporation, the American Academy of Otolaryngology and Head and Neck Surgery participated in a survey conducted by the Harris Interactive Group to explore parental attitudes and knowledge of obstructive sleep apnea and adenotonsillectomy.

2. Materials and methods

In April 2005, the Harris Interactive Group performed an independent survey, questioning 584 parents in the United States. Parents over 18 years of age with a child less than 18 years of age participated in a voluntary on-line survey. Respondents were divided into two groups, depending on whether their child had undergone tonsillectomy. There were 261 whose child had undergone adenotonsillectomy and 323

whose child had not undergone the procedure. The data were weighted to known norms for age, education level, income, and region. When the Harris Interactive group looked at attitudes of all the parents, they performed a weighted average based on the estimated ratio of tonsillectomy parents to non-tonsillectomy parents (1:9, or 11.4% tonsillectomy incidence). Questions included parental knowledge of severity of OSA, understanding of implications of respiratory difficulty during sleep, and understanding of the role of tonsils and adenoids in obstructive sleep disorders. Parents were also asked about systemic and behavioral deficits associated with obstructive sleep disorders. Lastly, they were surveyed regarding current prevalence of tonsillectomies in the United States. The data herein were first presented in the American Academy of Otolaryngology-Head and Neck Surgery Bulletin in July 2005 [10].

3. Results

Ninety-five percent of parents acknowledged that OSA as a serious condition, however only 15% considered themselves to be “knowledgeable” and only 1% to be “very knowledgeable” about it. Eighty-four percent recognized that interrupted breathing during sleep is a sign of OSA and 63% understood that gasping for air is another sign of OSA. However, there was a discrepancy between parents whose children had undergone tonsillectomy, and parents whose children had not undergone the procedure in

recognizing snoring (68% of the former group versus 58% of the latter) and mouth-breathing (50% of tonsillectomy parents versus 44% of non-tonsillectomy parents) as symptoms of sleep disordered breathing (SDB). Additionally, 48% of parents whose children had undergone tonsillectomy recognized enlarged tonsils to be related to SDB as compared to 36% of parents whose children did not have a tonsillectomy. Although there is no statistically significant difference between the groups, it demonstrates that parents of a child who has undergone a tonsillectomy are more knowledgeable and aware of the symptoms of sleep-disordered breathing. The majority of both groups did not recognize that daytime somnolence or daytime irritability might be signs of SDB. Only 38% recognized these as potential sequelae of OSA (Fig. 1).

Few parents understood the breadth of complications that could occur if sleep disordered breathing went untreated. While the majority did recognize sleep deprivation (78%) and irritability (60%) as long-term consequences of SDB, only half were aware that SDB could cause poor academic performance and 54% knew that OSA could cause motor vehicle accidents due to fatigue. Even fewer identified behavioral problems as a consequence of SDB (47%), with 33% recognizing depression and 40% recognizing “acting-out” as potential results of untreated SDB. One quarter believed memory loss to have a potential association of SDB (Fig. 2).

Few parents understood the serious impact of untreated obstructive sleep apnea. Only one fifth of parents identified cardiopulmonary problems,

Only 38% of parents know enlarged tonsils are a symptom of sleep-disordered breathing, such as pediatric sleep apnea.

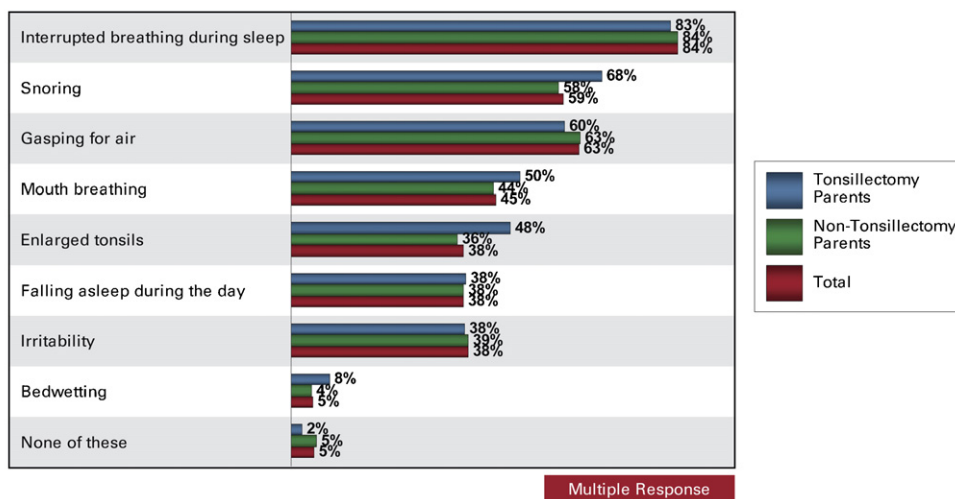


Fig. 1 Symptoms of sleep-disordered breathing, such as pediatric obstructive sleep apnea.

Less than half (47%) of parents know behavior problems are a consequence of not treating sleep-disordered breathing, such as pediatric obstructive sleep apnea.

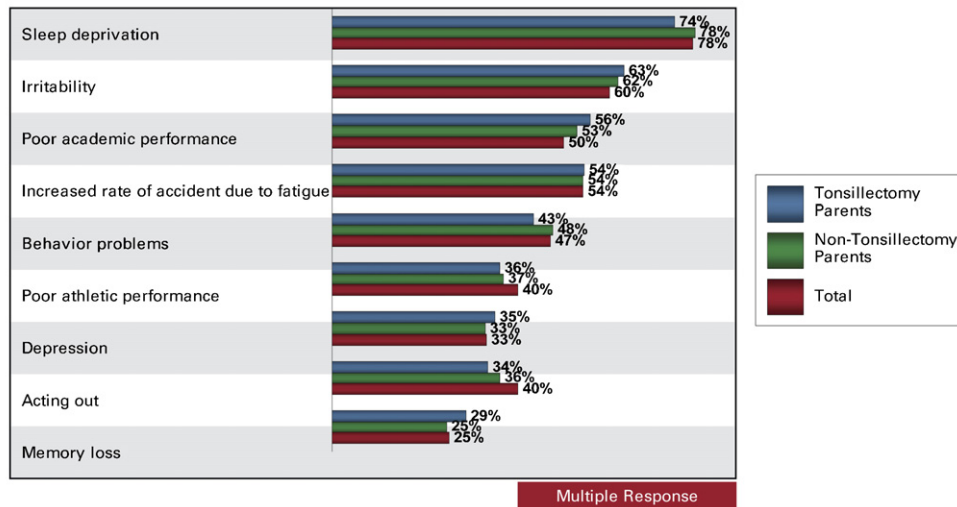


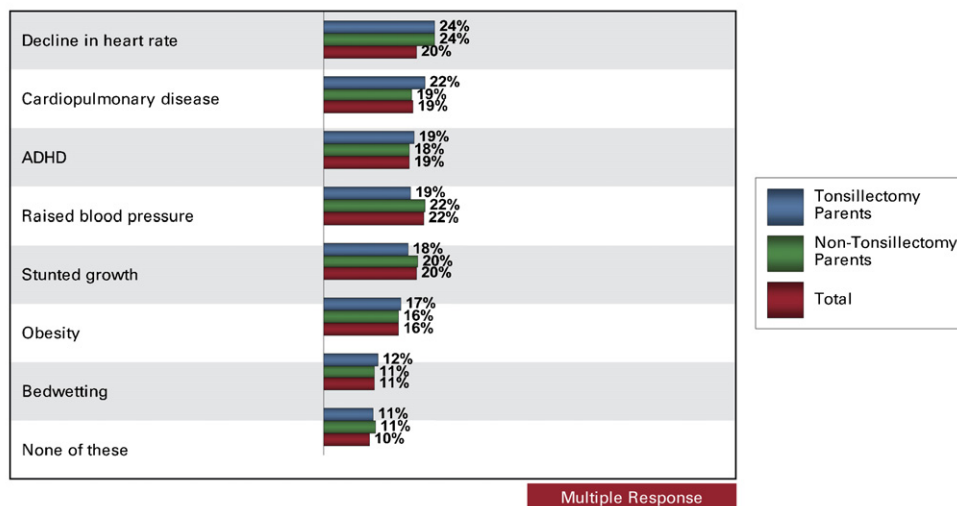
Fig. 2 Potential consequences of not treating sleep-disordered breathing, such as pediatric obstructive sleep apnea.

elevated blood pressure, growth delay, attention deficit hyperactivity disorder-like behavior, and obesity as potential complications of untreated OSA. As a whole, only 18% of parents appreciated that adenotonsillectomy could treat obstructive sleep apnea. When broken down into the two groups, 46% of parents whose child underwent adenotonsillectomy understood it could treat OSA, as

compared to 14% of “non-tonsillectomy” parents (Fig. 3).

Sixty-one percent of parents believed that they were “knowledgeable” about the prevalence of tonsillectomy, and 14% believed that they were “very knowledgeable”. However, only 6% correctly identified the approximate number of tonsillectomies performed each year in the United States

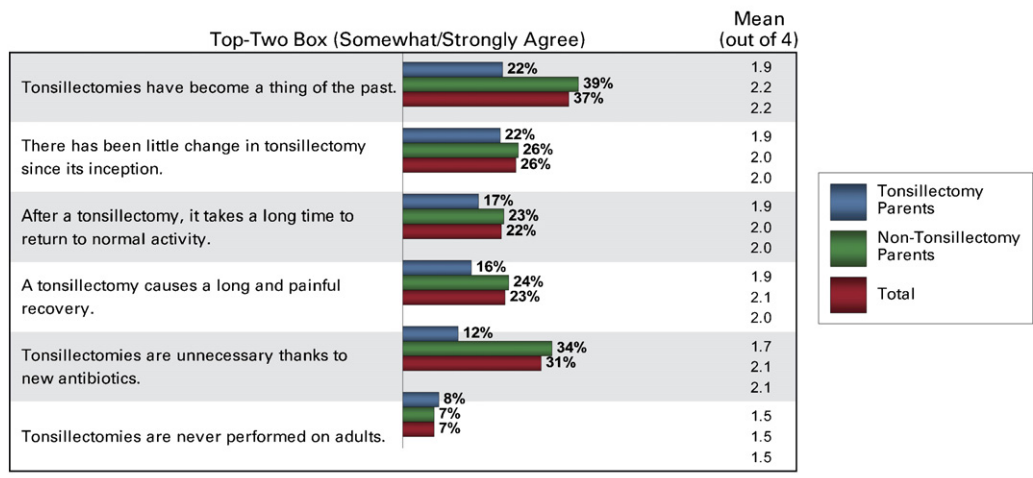
More than 80% of parents do not recognize ADHD as a potential consequence of not treating sleep-disordered breathing such as, pediatric obstructive sleep apnea.



Base: Tonsillectomy Parents (n=261); Non-Tonsillectomy Parents (n=323); Total Parents (n=584)
 Q605 As far as you know, which of the following are potential consequences of not treating pediatric obstructive sleep apnea? Please select all that apply.

Fig. 3 Potential consequences of not treating sleep-disordered breathing, such as pediatric obstructive sleep apnea, continued.

Two in five non-tonsillectomy parents (39%) believe that tonsillectomies are a thing of the past. Fewer than one in four tonsillectomy parents (22%) share this belief.



Base: Tonsillectomy Parents (n=261); Non-Tonsillectomy Parents (n=323); Total Parents (n=584)
 Q595 Please indicate how strongly you agree or disagree with each of the following statements.

Fig. 4 Tonsillectomy attitudes.

to be 600,000. Thirty percent of parents believed that tonsillectomies are “a thing of the past”. Thirty-one percent believed tonsillectomies have become unnecessary due to the use of antibiotics. Twenty-three percent of parents believed that tonsillectomy is an “old-fashioned” procedure and 16% felt it is “outdated”. Fewer parents whose child had undergone tonsillectomy held these beliefs, with only 22% believing tonsillectomies were outdated, and only 12% believing tonsillectomies were unnecessary secondary to the use of antibiotics. One fourth believed that there has been little change in how tonsillectomies are performed. However, 95% of parents were interested in a tonsillectomy procedure that would cause less pain and a faster recovery time (Fig. 4).

4. Discussion

Many parents have misconceptions regarding the significance of sleep-disordered breathing and the utility of adenotonsillectomy for treating the associated symptoms. This is not surprising, as even pediatricians have limited training and understanding of the symptoms and consequences of sleep disordered breathing and its prevalence [14]. The misconceptions of the general public make counseling parents regarding tonsillectomy for their children more difficult. With parents believing that tonsillar enlargement can be treated with antibiotics and is not related to sleep disordered breathing,

it can be challenging to have them consider their child undergoing a procedure, which they believe to be “outdated”. However, as many parents are interested in a procedure that will cause less pain and faster recovery than tonsillectomies of their generation’s childhood, the otolaryngologist can educate them on advances in surgical and anesthetic techniques.

Goldstein et al. demonstrated the impact on behavior and quality of life of adenotonsillectomy in children with obstructive sleep apnea [11,10]. Children with obstructive sleep apnea were more likely to have scores reflecting behavioral problems on the child behavior checklist (CBCL). The CBCL is a standardized measure of children’s behavior, which has questions addressing attention, aggression, anxiety, depression, and thought problems. Post-adenotonsillectomy CBCL scores reflected an improvement in behavior, with few subjects falling into the abnormal range after the intervention [12]. A follow-up study, comparing children with OSA to children undergoing non-adenotonsillar elective surgery, showed significant negative impact of OSA on behavior and quality of life (QOL), with a borderline or abnormal total problem score on CBCL in 29% of OSA subjects pre-operatively. Post-adenotonsillectomy, the QOL and CBCL scores for the children with OSA became more similar to the pre-operative scores of the control group, whose scores did not change after undergoing their surgical procedure [13]. Mitchell and Kelly used the behavior assessment system for children (BASC) to assess behavior changes after adenotonsillectomy.

They also found significant reduction in depression, hyperactivity and somatization after intervention [14].

The impact of sleep disordered breathing on cognitive function has also been of interest in recent studies. Gozal evaluated 297 first-grade children with poor academic performance. Fifty-four of these children were diagnosed with sleep-associated gas exchange abnormalities (SAGEA) after home sleep screening with pulse oximetry and transcutaneous partial pressures of CO₂. Twenty-four, chose to undergo adenotonsillectomy. Those who underwent adenotonsillectomy were found to have statistically significant improvement in their grades the following year, as compared to the 30 children whose parents opted for no intervention [15]. Additionally, Gozal studied children with poor performance in middle school and found that frequent loud snoring was more prevalent in children who were in the lower 25% of the class than children who were in the top 25% of the class. He also found that more children in the poor performance group had previously undergone adenotonsillectomy for SDB, suggesting that the cognitive losses may be only partially reversible [16]. A recent review by Halbower demonstrated that even children with mild OSA have deficits on verbal memory, learning, and vocabulary, and have executive control dysfunction or conduct problems. They suggested that hypoxia, even of short duration, is adequate to produce serious deficits in cognitive function in the child's rapidly developing brain [17].

Treatment of obstructive sleep apnea has a significant impact on health care utilization and costs. Tarasiuk found that children with OSA had 2.5 times the health care costs as compared to matched controls. Seventy-five percent of these costs were related to emergency room visits, hospital admissions, and consultations with a specialist, most often an otolaryngologist or pulmonologist. The children with OSA who underwent adenotonsillectomy had a 32% reduction in health care expenditures the year following the surgical procedure with a 50% reduction in upper respiratory infections. There were no changes in health care utilization for the control group or for the children with OSA who did not undergo adenotonsillectomy [18]. Education of the general public and primary care physicians regarding sleep disordered breathing and treatments should have a significant effect on public health.

5. Conclusion

The survey we present, in addition to the surveys of pediatricians, demonstrates that otolaryngologists

need to be pro-active in educating both pediatricians and parents. Sleep disordered breathing and obstructive sleep apnea can have serious consequences for a child's physical and mental health, as well as on the quality of life for both the parent and child. Without adequate screening of children for the more subtle signs of sleep disordered breathing, children may not undergo evaluation and treatment essential to prevent long-term sequelae, such as poor academic performance or behavioral problems. If pediatricians are more aware of the spectrum of severity of sleep disordered breathing and its impact on quality of life, they are more likely to screen children and, when necessary, refer to sleep specialists and/or otolaryngologists for diagnosis and treatment. Pediatricians can educate families regarding the significance of sleep-disordered breathing, signs and symptoms of the disorder, and the need for treatment when it is diagnosed. Education regarding sleep disordered breathing and adenotonsillectomy is greatly needed, and will have a significant impact on general public health.

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