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Parental Perceptions of Sleep Disturbances and Sleep-Disordered Breathing in Children With Down Syndrome

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Abstract

Objectives: Children with Down syndrome (DS) have increased difficulty initiating and maintaining sleep (DIMS), excessive daytime sleepiness (EDS), and obstructive sleep apnea (OSA). As part of a quality improvement initiative, parents of children enrolled in the Children's Hospital Boston Down Syndrome Program were surveyed about their child's sleep and breathing patterns while asleep. *Methods:* An anonymous Internet-based questionnaire was used in the study. *Results:* The completion rate was 46.5% (255/548). DIMS and EDS were frequently/almost always present in more than half the children. Among parents unconcerned about their child's breathing, 11.8% witnessed apnea and 4.2% gasping/choking more than once monthly. Parents of children status post adenotonsillectomy (AT) reported witnessed apnea (47.5%), gasping/choking (28.9%) more than once monthly. *Discussion:* There is room for improved screening of sleep disturbances, OSA in children with DS. The high frequency of persistence of OSA following AT should prompt for continued screening following AT.

Keywords

Down syndrome, sleep disorders, sleep disordered breathing, obstructive sleep apnea, pediatrics

Introduction

Children with Down syndrome (DS) are known to have an increased prevalence of sleep disturbances. These include difficulties in initiating and maintaining sleep (DIMS) and excessive daytime sleepiness (EDS),[1,2] and a 31% to 63% incidence of obstructive sleep apnea (OSA).[3,4] Disordered sleeping patterns leading to insufficient sleep and to EDS can significantly affect daytime function, cognitive abilities,[5] and behavior.[6] OSA has been demonstrated to cause hypertension,[7] poor glucose tolerance,[8] increased heart disease,[9] pulmonary hypertension,[10] and in children to adversely affect behavior,[11] cause cognitive deficits,[12] and developmental delay.[13]

The Down Syndrome Program (DSP) at Children's Hospital Boston provides comprehensive, ongoing care to children between birth and age 18 years, and in 2009 had 254 patient visits. As part of a quality improvement initiative to better address the needs of these children in the areas of sleep and sleep disordered breathing, the parents of children connected with the DSP were asked to complete a 10-item questionnaire (see the appendix) about their child's sleep habits, breathing patterns while asleep, their degree of concern about their child's sleep and breathing, and whether they had undergone a sleep study and/or adenotonsillectomy (AT).

Methods

An email was sent out to the 548 parents on the DSP distribution list (which includes the majority of children followed in the DSP as well as patients who have requested receiving updates from the program) explaining

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Table 1. Survey Questions and Their Responses[a]

	(see Figure 1)			
What is your child's age?	Never	Sometimes	Frequently	Always
Does your child have difficulties *falling* asleep? (n = 253)	122 (48.2)	109 (43.1)	14 (5.5)	8 (3.2)
Does your child have difficulties *staying* asleep? (n = 252)	77 (30.6)	108 (42.9)	37 (14.7)	30 (11.9)
Does your child have excessive daytime sleepiness? (n = 250)	115 (46.0)	105 (42.0)	26 (10.4)	4 (1.6)
	Less Than Once a Month	More Than Once a Month	More Than Once a Week	Almost Every Night
Have you witnessed apneic pauses while your child sleeps? (n = 238)	152 (63.9)	41 (17.2)	24 (10.1)	21 (8.8)
Have you witnessed choking or gasping while your child sleeps? (n = 233)	187 (80.3)	27 (11.6)	15 (6.4)	4 (1.7)
	None	Not Discussed	Yes, Discussed	
Do you have concerns about child's breathing, and if so, have you discussed them with his her physician? (n = 248)	119 (48.0)	19 (7.7)	109 (44.0)	
	Yes	No		
Have you ever discussed concerns about your child's sleep with her/his MD (n = 250)	148 (59.2)	102 (40.8)		
Has your child ever had a sleep study (n = 249)	88 (35.3)	161 (64.7)		
Has your child had her/his tonsils and/or adenoids removed (n = 250)	83 (33.2)	167 (66.8)		

[a]Figures in parentheses are percentages.

the purpose of the quality improvement (QI) initiative and directing them to an Internet-based questionnaire (http://www.surveymonkey.com) containing 10 questions (Table 1). A reminder email was sent 5 days later asking those who had not yet completed the questionnaire to please do so. The questionnaire was anonymous, and it was clearly stated that there would be no way of knowing who had elected to participate or not, and that whether or not they completed it would have no effect on their child's continued care in the DSP. As this was a QI initiative, it was granted an exemption by the Children's Hospital Boston Internal Review Board from formal review.

Results

In all, 255 of the 548 parents contacted (46.5%) responded to the survey, with 241 answering all of the questions (Table 1). The average age of the children was 5 years 8 months, and the median age was 5 years old (Figure 1), not including the 4 who were age 18 years and older.

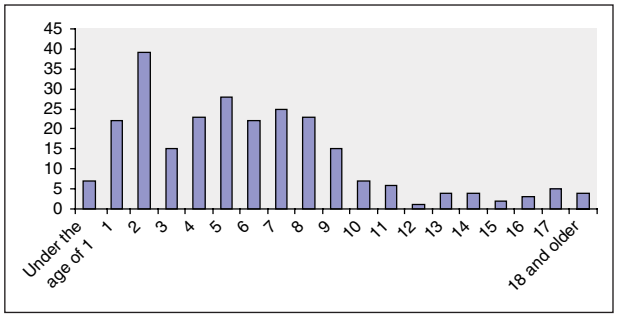

Figure 1. Ages of children of respondents

Difficulties initiating sleep were reported in 131/253 (51.8%), with 14 (5.5%) described as "frequently" and 8 (3.2%) as "almost always." A total of 175 of 252 (69.4%) reported difficulties maintaining sleep, with 37 (14.7%) described as "frequently" and 30 (11.9%) as "almost

Table 2. Incidences of DIMS, EDS in Children Whose Parents Had *Not* Discussed Their Child's Sleep With Their Physician

	Frequently	Almost Always	Total	Percentage
Difficulties falling asleep (n = 22)	1	1	2	9.0
Difficulties staying asleep (n = 66)	12	6	18	27.3
Excessive daytime sleepiness (n = 29)	9	1	10	34.5

Abbreviations: DIMS, difficulty initiating and maintaining sleep; EDS, excessive daytime sleepiness.

Table 3. Incidence of Witnessed Apnea and Choking or Gasping in Children Whose Parents Were Not Concerned by It or Were Concerned and Had Not Discussed It With Their Child's Physician

	More Than Once a Month	More Than Once a Week	Almost Every Night	Total	Percentage
No concerns about child's breathing (n = 119)					
Witnessed apnea	7	5	2	14	5.8
Gasping or choking	3	2	0	5	4.2
Concerns about child's breathing not discussed (n = 19)					
Witnessed apnea	4	4	1	9	47.4
Gasping or choking	1	2	0	3	15.8

Table 4. Incidence of Witnessed Apnea and Choking or Gasping in Children Who Had Not Undergone a Sleep Study

	More Than Once a Month	More Than Once a Week	Almost Every Night	Total	Percentage
Witnessed apnea (n = 151)	19	14	8	41	27.2
Witnessed choking or gasping (n = 145)	12	6	1	19	13.1

always." A total of 135 of 250 (54%) children were reported to have excessive daytime sleepiness, with 26 (10.4%) described as "frequently" and 4 (1.6%) as "almost always." Overall, 148/250 (59.2%) of respondents reported having discussed their child's sleep with their physician. 2/67 (3%) of those whose children were reported to "frequently" or "almost always" have difficulties initiating sleep, 18/66 (27.3%) of those whose children were reported to "frequently" or "almost always" have difficulties maintaining sleep, and 10/29 (34.5%; Table 2) of those whose children were reported to "frequently" or "almost always" have EDS had not discussed these concerns with their child's physician.

A total of 119 of 248 (48%) reported having no concerns about their child's breathing while asleep, 19 (7.7%) reported having concerns which they had not discussed with their child's physician, and 109 (44%) reported having discussed their concerns with their child's physician. Of those who stated they were not concerned about their child's breathing, 14/119 (11.8%) reported witnessing apnea more than once a month, and 5 (4.2%) reported witnessing choking or gasping more than once a month (Table 3). Of those who stated they were concerned about their child's breathing while asleep but had not discussed these concerns with their child's physician, 9/19 (47.4%) reported witnessing apnea more than once a month, and 3 (15.8%) noted gasping or choking more than once a month.

In all, 88/249 (35.3%) of the children had undergone a sleep study in the past. Of those 161 who had not, 41 (27.2%) were reported to have had witnessed apnea more than once a month, and 19 (13.1%) were reported to gasp or choke during sleep more than once a month (Table 4).

In total, 83/250 (33.2%) of the children had undergone adenotonsillectomy (AT). Of those who had undergone AT, 38 (47.5%) continued to have witnessed apnea more than once a month, and 22 (28.9%) continued to gasp or choke during sleep more than once a month (Table 5).

Discussion

Although targeted questions about sleep and sleep-disordered breathing are routinely asked both in advance

Table 5. Incidence of Witnessed Apnea and Choking or Gasping in Children Who Had Had Their Adenoids and/or Tonsils Removed

	More Than Once a Month	More Than Once a Week	Almost Every Night	Total	Percentage
Witnessed apnea (n = 80)	18	8	12	38	47.5
Witnessed choking or gasping (n = 76)	13	6	3	22	28.9

of clinic visits in the DSP by way of a written intake form as well as during the visits themselves, a sizable number of parents reported concerns about their child's sleep patterns and breathing during sleep, which they had not discussed with their child's physicians.

The finding that 47.5% of children who had undergone AT had witnessed apnea and 28.9% had gasping or choking during sleep at least once a month is consistent with previously reported findings that AT is generally much less effective in treating OSA in children with DS as a group.[14] This underscores the need for continued monitoring for persistence or recurrence of signs and symptoms of sleep-disordered breathing in children with DS even after they have undergone AT.

Although the response rate to this survey was relatively high, the results cannot be seen to represent the perceptions of all parents of children in the DSP. It is also not possible to extrapolate them to what may be the general state of sleep disturbances and sleep-disordered breathing in children with DS elsewhere. Fewer than half of the children whose parents were invited to participate had been seen in the DSP during the previous year, during which targeted questions about sleep began to be asked routinely. Because this was the first time that this questionnaire was used, there are no data with which to compare these results, for example, with those which might be obtained by querying parents of typical children. As parental descriptions of symptoms of OSA do not always correlate with findings on overnight sleep study,[15] the high percentage of parents reporting symptoms concerning for OSA may not necessarily indicate the presence of clinically significant disease. Finally, one cannot be certain that the parents were referring to their child's physician in the DSP, and not their child' pediatrician.

Despite these limitations, however, the findings indicate a need for more to be done to educate families of children with DS about DIMS, EDS, OSA and their consequences, and to better elicit this information so that these disorders can be appropriately diagnosed and treated.

Appendix

Text of Questionnaire

1. How old is your child?
2. Does your child have difficulties *falling* asleep at night? (never, sometimes, frequently, almost always)
3. Does your child have difficulties *staying* asleep at night? (never, sometimes, frequently, almost always)
4. Does your child appear to be excessively sleepy during the daytime to you or her/his teachers at school? (never, sometimes, frequently, almost always)
5. Have you ever discussed your child's sleep with your physician? (yes, no)
6. Do you ever hear pauses in your child's breathing while asleep? (less than once a month, more than once a month but less than once a week, a few times a week, almost every night)
7. Do you ever notice your child gasping or choking while asleep? (less than once a month, more than once a month but less than once a week, a few times a week, almost every night)
8. If you do have concerns about your child's breathing while asleep, have you ever discussed them with your child's physician? (No, I do not have any concerns about my child's breathing; I have concerns about my child's breathing, but have not discussed them with my child's physician; Yes, I have discussed my concerns with my child's physician)
9. Has your child ever had a sleep study? (yes, no)
10. Has your child had her/his tonsils and/or adenoids removed? (yes, no)

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