Do Urban Minority Parents and Children Agree on Asthma Symptoms with Exercise, Worries, and Confidence in Disease Management?

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Abstract

Objective: Providers commonly rely on parent reports of a child's asthma symptoms; however, children as young as 7 years can report on their own health. Our study compared parent and child reports of asthma symptoms with exercise, worries about developing an asthma attack, and confidence in disease management.

Methods: We recruited children ages 7 to 10 years with asthma from 4 Bronx, NY, schools, as well as their parents. The parents and children completed interview surveys with parallel questions regarding perceived asthma symptoms, asthma-related worries, and confidence in disease management. We used McNemar tests for paired data to compare parent and child responses.

Results: We analyzed data for 105 parent-child pairs. Mean child age was 8.5 years (standard deviation, 0.99); 53% were male, and 82% were Hispanic. Children were more likely than their parents to report ever having an exercise-induced asthma attack (85% vs 48%; $P < .001$) and that they "worry a lot" about developing an asthma attack during exercise (63% vs 45%; $P = .01$). Children felt more confident about using an inhaler correctly (76% of the children were "very sure" vs 60% of the parents; $P = .009$) and were more likely to report having an inhaler available in case of an attack (38% of the children were "very sure" vs 20% of the parents; $P = .003$).

Conclusions: In this school-based sample of urban children with asthma, we found disagreement between parent and child reports of symptoms with exercise, worry about developing an attack, and confidence in medication use. These findings suggest that including child reports during history taking could help providers identify children in need of enhanced asthma management.

Keywords: parent-child agreement; asthma; caregivers; pediatric; urban

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What's New?

Our results revealed parent-child disagreement regarding exercise-induced asthma symptoms, asthma-related worries, and confidence in disease management, suggesting that including children's reports during history taking could help providers identify children in need of enhanced asthma management and initiate conversations addressing such concerns.

Asthma, the most common pediatric chronic respiratory disease, affects approximately 7 million children in the United States.[1] The prevalence of asthma is higher among minority children living in inner cities, such as the Bronx, NY, where 20% to 25% of schoolchildren have asthma.[2,3] Many urban children with asthma experience poor symptom control, and asthma management remains a challenge.

Children as young as 7 years of age are able to report on their health status,[4] but physicians often rely only on parent reports to determine if a child experiences symptoms with exercise, especially for children younger than 12 years of age.[5−7] Previous studies analyzing parent and child agreement on asthma diagnosis, asthma symptoms, and quality of life show significant differences.[8−10] Whereas there is a high level of agreement between parents and children on the diagnosis of asthma, agreement varies with regard to reported asthma symptoms.[9,11,12] Although parent reports are important, parents can provide only an indirect account of their children's experiences, which may lead to an underestimation of asthma symptoms and activity limitations. This, in turn, may lead to suboptimal treatment plans, poor disease management, and decreased exercise.

Exercise is important for children with asthma and has been associated with decreased symptom severity, improved quality of life, and reduced school absenteeism.[13−17] Prior studies have revealed that children are more likely than parents to report wheezing during or after exercise,[18] but parents are less likely to report the

impact of exercise on the child's asthma.[10] There is no literature comparing parent-child reports on worry about developing an asthma attack with exercise or about using inhalers in front of others.

Asthma management often relies on many factors, including medication availability, proper medication use, and self-efficacy. There are multiple barriers to asthma management, especially in Hispanic and other urban minority populations.[19] Furthermore, asthma management is often a shared responsibility between parents and children. Previous studies examining parent reports of medication adherence have shown decreased adherence to medication use, especially in urban populations[19]; however, there is little literature comparing parent and child reports on medication use. A study comparing reports of medication use by children 10 to 12 years of age and their parents showed discrepancies.[10] In prior studies examining medication administration and the asthma management self-efficacy of parents and adolescents, the parents reported a higher level of confidence and self-efficacy on medication administration and lower confidence with more complex tasks involving judgment and decision making.[20–22] No studies, however, have explored parent-child agreement on child confidence and self-efficacy with regard to either having asthma medication available during an attack or its proper use.

By obtaining both parent and child reports, physicians may obtain a more complete picture of the frequency of asthma symptoms and medication use, as well as the impact asthma has on children and their families. There is scant literature comparing urban minority parent and child reports about asthma symptoms during exercise, worry about having an asthma attack and medication use, or self-efficacy in inhaler use. Thus, the objective of our study was to compare these types of parent and child reports among a school-based sample of urban minority children with asthma and their parents.

METHODS

PARTICIPANTS AND SETTINGS

This study used cross-sectional baseline data for children 7 to 10 years of age who were enrolled in a school-based asthma intervention trial and data from their parents. Prior to study enrollment, we identified children with asthma by conducting an asthma screening of all students attending second through fourth grades in 4 Bronx, NY, elementary schools.[3] To determine asthma intervention trial eligibility, research assistants completed a telephone screening with parents or primary caregivers who indicated that their children had asthma on the screening survey, and they described the study. Research assistants then met with each parent and child at school or at their home to obtain informed consent/assent and to complete the baseline survey. Families were eligible for participation if they had children 7 to 10 years of age who had 1) parent reports of an asthma diagnosis made by a physician; 2) prescriptions for asthma medication in the past 12 months; and 3) caregivers who spoke English or Spanish. (We use the terms "parent" and "caregiver" interchangeably in this report.) Children with other chronic pulmonary diseases, such as cystic fibrosis or bronchopulmonary dysplasia, were excluded.

The study was approved by the institutional review boards of both the Albert Einstein College of Medicine-Montefiore Medical Center and the New York City Department of Education. Written consent from caregivers and assent from children were obtained prior to study participation.

MEASURES

CHILD AND PARENT SURVEYS

All child and parent surveys were administered verbally, one-on-one, by trained research assistants. Child surveys were conducted at the school, and parent surveys (in English or Spanish) were administered either at school or at home. The child and parent surveys included parallel questions regarding perceived asthma symptoms with exercise and the child's competence in addressing them. Survey questions were developed based on the results of a qualitative study that explored barriers to exercise in children with asthma in a school setting,[23] on expert opinion, and on a literature review. Cognitive interviews were conducted with 3 children to test a child's understanding of the questions and answers. Questions were then revised based on the results of cognitive interviews. Each child survey proceeded by first asking the child to define "asthma attack," "exercise," "asthma medicine pump," and what it means to worry or to be sure of something. Definitions of these terms were then read to the child. An asthma attack was defined as asthma symptoms (cough, wheezing, shortness of breath) experienced by the child.

SURVEY QUESTIONS

Survey questions were adapted from several validated scales.[24–26] Survey questions asked about the child ever having an asthma attack with exercise (yes/no); the child's worries about developing an asthma attack during exercise, not having an asthma inhaler during an attack, or possible asthma-related stigma such as peers seeing the child use an inhaler and laughing at him/her or saying hurtful things (7 questions); and the child's self-efficacy or confidence in using an inhaler, inhaler availability in case of having an asthma attack during exercise, and the child's knowledge of which medication to use during an attack (7 questions).

Response categories for questions about the child's worries included "worry a lot," "worry somewhere in between," "worry a little," or "not at all." We dichotomized these responses into "high" ("worry a lot") and "low" ("worry somewhere in between," "worry a little," or "not at all"). Response categories for self-efficacy questions included "very sure," "a little bit sure," or "not sure at all." We dichotomized these responses into "very sure" or "not sure" ("a little bit sure" or "not sure at all").

Demographic Data

The parents provided information about the children's demographic characteristics, including age, gender, ethnicity (Hispanic, non-Hispanic), and race (African American, white, unspecified/other); duration of asthma diagnosis; medications prescribed by the child's primary care physician; and insurance status (Medicaid, not Medicaid), as well as several parental variables, including age, relationship to the child, ethnicity/race, whether the family was a single-parent household, history of asthma, and education ("less than high school," "graduated high school or GED," "some college [1−3 years]," or "college [4 years or more]"). Medication availability at school was assessed via New York City Department of Education Medication Administration Forms, which give permission to a school nurse to administer asthma medications to a student in school.[3]

Statistical Analysis

The level of agreement between children and parents on each pair of items was assessed by the kappa coefficient, a statistic that indicates whether agreement is beyond the level of chance.[27] We used weighted kappa when the items being compared had more than 2 categories; weighted kappa accounts for relative agreement of categories on an ordinal scale by allocating less weight to the categories further apart.[27,28] Kappa values less than 0.20 are considered to indicate slight or poor agreement; 0.21 to 0.40, fair agreement; 0.41 to 0.60, moderate agreement; 0.61 to 0.80, substantial agreement; and more than 0.80, almost perfect agreement.[28] We also used McNemar tests for paired data to determine whether the child and caregiver responses differed significantly. Findings with P values $\leq .05$ were considered statistically significant. Analyses were conducted using IBM SPSS Statistics 25 (IBM Corp; Armonk, NY).

Results

Demographic Characteristics

To identify potential participants, we screened 1270 students through caregiver-completed surveys sent home with students.[3] Of the 1270 surveys, 769 (61%) were returned. Overall, 192 children (25%) had physician-diagnosed asthma; of these, 158 met the criteria and were eligible for enrollment in the study. We enrolled 108 children and their parents (enrollment rate of 68%). Two children and their parents withdrew from the study prior to the baseline data collection. One child was discharged from the school prior to the baseline survey completion.

Survey responses were evaluated for the 105 parent-child pairs for whom data were available. Table 1 provides the demographic characteristics of the participants. The mean age of children was 8.5 years (range, 7−11 years), and the average duration of asthma diagnosis was 6.4 years. Slightly over half of the children were male (53.3%), and 81.9% had a Hispanic background. Over 90% of the parents were mothers, and 41.9% indicated having asthma themselves.

Table 1. Child and Caregiver Demographics (N = 105 dyads)*

Demographic	Value
Child	
Child age (y), mean ± SD	8.5 ± 0.99
Sex, n (%)	
Male	56 (53.3)
Ethnicity, n (%)	
Hispanic	86 (81.9)
Non-Hispanic	19 (18.1)
Race, n (%)	
African American	30 (28.6)
White	13 (12.4)
Unspecified/other, n (%)	62 (59.0)
Duration of asthma diagnosis (y), mean ± SD	6.4 ± 2.4
Insurance, n (%)	
Medicaid	90 (85.7)
Reported medication prescription, n (%)†	
Rescue inhaler only	41 (39.0)
Controller + rescue inhalers	60 (57.1)
Medication availability in school based on MAF forms, n (%)‡	24 (22.4)
Severity-control classification, n (%)§	
Intermittent or well controlled	25 (23.8)
Mild to moderate persistent or not well controlled	52 (49.5)
Severe persistent or poorly controlled	28 (26.7)
Caregiver	
Caregiver age (y), mean ± SD	36.2 ± 6.9
Relationship, n (%)	
Mother	99 (93.9)
Ethnicity, n (%)	
Hispanic	80 (76.2)
Non-Hispanic	25 (23.8)
Race, n (%)	
African American	29 (27.6)
White	13 (12.4)
Unspecified/other	63 (60.0)
Single-parent household, n (%)	59 (56.2)
History of asthma diagnosis, n (%)	44 (41.9)
Caregiver education, n (%)	
Less than high school	34 (32.4)
Graduated high school or GED	26 (24.8)
Some college (1−3 y)	36 (34.3)
College (4 y or more)	9 (8.6)

GED indicates General Education Development; MAF, medication administration form; and SD, standard deviation.

*Of the 105 parent participants, 36 required surveys to be administered in Spanish.

†Caregivers of 4 participants did not report a rescue inhaler prescription.

‡Data were available on 107 students.

§As per National Heart, Lung, and Blood Institute asthma diagnosis and management guidelines,[29] asthma severity was identified for children who were on rescue medication only, and asthma control level was assessed for children who were prescribed preventive medications.

Child and Parent Agreement on Asthma Attack with Exercise

Children were significantly more likely than parents (84.6% vs 48.1%) to report that the child had ever had an asthma attack with exercise ($P < .001$). The kappa statistic (0.03) indicated poor agreement between children and parents on this item.

CHILD AND PARENT AGREEMENT ON ASTHMA-RELATED WORRIES

As shown in Table 2, there were significant differences between parents and children on 4 of the 7 questions that assessed the perception of being worried about asthma. Children were more likely than their parents to report that they "worry a lot" about developing an asthma attack during exercise, about other children seeing them take medication, and about other children laughing at them or saying hurtful things. Parents were more likely than children to say they "worry a lot" that the child would not stop wheezing when he/she exercises. Weighted kappa statistics (−0.03 to 0.14) indicated poor parent-child agreement for all questions pertaining to perception of risk.

CHILD AND PARENT AGREEMENT ON CHILD'S ASTHMA SELF-EFFICACY

Table 3 shows parent-child agreement on a child's self-efficacy in managing and preventing an asthma attack, including medication availability during an attack and confidence in using an inhaler. Children were more likely than their parents to say they were "very sure" that they would have an inhaler available in case of an asthma attack and know how to use it correctly. Compared to their parents, children also were more likely to feel "very sure" that they could slow down during exercise to prevent an attack and would know what to do during an attack when parents were not present with them. Parent-child responses did not differ on perceptions of the child's ability to know which medication to use in case of an attack. This pattern did not change in comparisons of parent-child responses when children were prescribed both controller and rescue inhalers versus a rescue inhaler only. Low kappa coefficients (−0.02 to 0.18) indicated poor agreement between parent and child responses for all 7 asthma self-efficacy questions.

DISCUSSION

Our study findings suggest disagreement between children with asthma and their parents on the topics of symptoms with exercise, feelings of worry, and confidence in managing and preventing asthma exacerbation. Children were more likely to report symptoms with exercise and greater worry about developing an asthma attack when they exercise, but parents were more worried that their children would not stop wheezing when they exercise. Children also expressed greater concern about stigmatization (feelings of worry that peers would see them use an inhaler and laugh at them or say hurtful things) but more confidence in their ability to manage and prevent an asthma attack.

In concordance with our findings, the literature suggests that parents under-report their child's asthma symptoms with exercise.[10,12,18,30] Children and teenagers have been found to report more symptoms with exercise, such

Table 2. Asthma-Related Worry

Question Topics	Child Question	Child Response of "A Lot"	Caregiver Question	Caregiver Response of "A Lot"	McNemar *P* Value
Worry about developing an asthma attack during exercise	How worried are you that you will get an asthma attack when you exercise?	62.5%	How worried are you that your child will get an asthma attack when he/she exercises?	45.2%	.011
Worry about inhaler availability	How worried are you that you will need your asthma medicine pump but not have it with you?	44.8%	How worried are you that your child will need his/her asthma medication pump but not have it?	55.2%	.161
Worry that other children will see medication administration	How worried are you that other children will see you using your asthma medicine pump?	21.0%	How worried are you that other children will see your child using his/her asthma medication pump?	9.5%	.029
Worry that other children will laugh or say hurtful things	How worried are you that other children will laugh at you or say hurtful things?	64.4%	How worried are you that other children would laugh at him/her or say hurtful things to him/her?	41.3%	.001
Worry about coughing during exercise	How worried are you that you will not stop coughing when you exercise?	44.2%	How worried are you that your child will not stop coughing when he/she exercises?	55.8%	.134
Worry about wheezing during exercise	How worried are you that you will not stop wheezing or have noisy breathing in your chest when you exercise?	47.1%	How worried are you that your child will not stop wheezing or have noisy breathing in his/her chest when he/she exercises?	63.5%	.033
Worry about the risk of an asthma attack when running up stairs	How worried are you that you will get an asthma attack when you run up stairs?	46.7%	How worried are you that your child will get an asthma attack when he/she runs up stairs?	50.5%	.659

Table 3. Asthma Self-Efficacy

Question Topics	Child Question	Child Response of "Very Sure"	Caregiver Question	Caregiver Response of "Very Sure"	McNemar *P* Value
Inhaler availability	Let's imagine you do exercise and you start having an asthma attack. How sure are you that you will have your asthma medicine pump with you?	38.1%	Let's imagine your child does exercise and he/she starts having an asthma attack. How sure are you that he/she will have his/her asthma medication pump with him/her?	20.0%	.003
Inhaler use confidence	How sure are you that you can use your asthma medicine pump correctly?	76.2%	How sure are you that your child can use his/her asthma medication pump correctly?	60.0%	.009
Medication knowledge	Let's imagine you are having an asthma attack. How sure are you that you will know which medicine to use?	41.3%	If your child is having an asthma attack, how sure are you that he/she will know which medication to use?	49.0%	.291
Child asthma attack management when alone	Imagine you are having an asthma attack and your parents are not with you. How sure are you that you would know what to do?	48.5%	If your child has an asthma attack and you are not with him/her, how sure are you that your child will know what to do?	30.1%	.008
Child asthma attack prevention	Imagine you are having an asthma attack. How sure are you that you can keep your asthma from getting worse?	26.5%	If your child is having an asthma attack, how sure are you that your child can keep his/her asthma from getting worse?	17.6%	.175
Child asthma attack management during exercise	Imagine you do exercise and you start having an asthma attack. How sure are you that you would know what to do?	48.5%	Let's imagine your child does exercise and he/she starts having an asthma attack. How sure are you that he/she will know what to do?	40.8%	.302
Child asthma attack prevention during exercise	How sure are you that you can slow down when you exercise to prevent an asthma attack?	56.2%	How sure are you that your child will slow down when he/she exercises to prevent an asthma attack?	40.0%	.030

as coughing, wheezing, and breathing problems, than their parents report.[10,12,18,30] Parent reports of child symptoms may vary because most school-aged children are away from their parents for many hours during the day. School-aged children spend approximately 6.5 hours in school each day away from their parents, and 28% of New York City children spend additional time in afterschool programs.[31,32] It is not unusual for children to participate in physical activities during gym class or recess, which may exacerbate their asthma.[33] Although parent reports are important, our findings and those of prior research suggest that obtaining both parent and child reports may provide a more complete picture of how asthma impacts children and their families.[34]

Due to the amount of time children spend in school, parents may not be aware of their child's symptoms, the child's use of medication while in school, or the child's relationships with peers. Our results indicate that children are more likely than their parents to report asthma symptoms with exercise; thus, it would be logical that children worry more that they will develop symptoms and fear stigmatization when participating in sports alongside their healthy peers. This coincides with our findings that children report greater worry about stigmatization and are more likely to report these feelings than parents. Other studies have also shown that elementary school children and adolescents have reported feelings of worry and embarrassment about taking their medication in the presence of other children.[23,35] The stigma and worry associated with asthma symptoms during exercise may lead to avoidance of physical activity. Based on National Heart, Lung, and Blood Institute guidelines, it is important to promote exercise in children with asthma.[29] Physicians play an important role in promoting physical activity in this population by ensuring proper medication prescription (eg, pre-exercise rescue inhaler) and evaluating medication technique and adherence, in addition to providing education to parents and children. Obtaining reports from children may shine light on this issue and give parents and physicians the ability to address stigma, thereby promoting exercise; however, there is a lack of studies comparing parent and child reports of worry about having an asthma attack and using asthma medications.

Although our study showed that children were more worried about issues related to their asthma, they were more confident about their abilities to manage symptoms,

slow down during exercise to prevent exacerbation, and correctly use the inhaler than their parents felt they would be. Studies also have shown that parents and children separately feel confident in asthma inhaler technique as well as in managing asthma attacks.[20,22] Also, separate studies show that there is a positive correlation between self-efficacy and asthma control in parents[36] and minority teenagers.[37] When previous studies of mainly white participants from non-US countries examined self-efficacy in medication administration techniques among school-aged children[21,22,38] and parents of school-aged children,[20,39] they found poor inhaler technique in this population. A study of mainly African American and Hispanic teens and caregivers found that teens were less likely to identify correct medication, but there was no difference between teens and caregivers in correctly describing indications for medication use.[40] Based on these studies, although children may feel confident in their ability to identify and use an inhaler, it has been shown that their confidence may be misguided. This highlights the need to evaluate a child's confidence and beliefs and correlate them to the self-efficacy of the child. It has been recommended that physicians increase communication directly with children about medications,[41] but there is a lack of literature comparing inner-city, minority parent and child reports on confidence in asthma management and medication administration.[36]

Our study had some limitations. It was conducted in urban public elementary schools in the Bronx, NY, which is predominately Hispanic; thus, the conclusions may not be generalizable to non-minority children in other schools or in different communities. It is possible that some children who were not physically fit may have incorrectly reported their shortness of breath as being an asthma-related symptom. This misconception may lead to an increase of affirmative responses regarding asthma symptoms experienced by children. Additionally, questions reflecting confidence or worry regarding asthma inhaler use or availability did not specify use of a spacer along with the inhaler. Finally, it is unclear if the children's or parents' perceptions are more accurate or whether the children's higher levels of confidence that we observed are warranted.

CONCLUSIONS

Children were more likely than their parents to report that they had exercise-induced asthma symptoms and concerns about exacerbation during exercise. Parents felt less confident about their children using an inhaler correctly and about having an inhaler with them in case of an asthma attack. These findings suggest that including children's reports regarding symptoms with exercise and worries about embarrassment and assessing their inhaler technique during visits might help providers to identify those in need of enhanced asthma management, address parent and child concerns, and open conversations about stigma. The differences in parent and child responses indicate that communication about asthma, particularly in the context of exercise, among the child, parent, and physician is warranted.

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