

Is Johnny wheezing? Parent–child agreement in the Childhood Asthma in America survey

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We compared responses of children and parents to determine their level of agreement in a national, population-based survey regarding asthma-related health of US children. A telephone-based survey was conducted in 2004 among a national probability sample of children with current asthma in the United States. To compare responses between parent–child pairs, a subset of 284 children aged 10–15 were interviewed in addition to the parents. This survey collected data on asthma symptom prevalence, physical activity limitations and impact of exercise on asthma, and asthma management including medication use. Paired responses were compared using the kappa (κ) statistic. Overall, parents of 10–15-yr-olds underestimated the burden of asthma experienced by their children, especially the effects on physical activity. More than half (58%) of children replied that exercise was a trigger for their asthma compared to only 35% of parents (κ 0.23). Children were more likely than parents to mention activity limitations, specifically avoiding physical exertion (63% vs. 49% – κ 0.004). Prevalence of symptoms was also underreported by parents relative to children, particularly breathing problems (41% vs. 67% – κ 0.16) and cough (45% vs. 64% – κ 0.14). Maintenance therapy use in the past 4 weeks was reported by 35% of children, whereas 44% of parents believed their children had used maintenance therapy (κ 0.47). Relative to children's self-report, parents underestimated avoidance tactics used by their children with asthma, including exercise and physical activity self-limitation to prevent the onset or worsening of asthma symptoms. Parents also underreported asthma symptoms of their children aged 10–15 years old and were discordant with their children regarding medication use. Increasing regular communication about asthma between child, parent, and physician is warranted to improve asthma control and overall health.

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Optimal asthma control in pediatric patients is an ongoing challenge for parents, physicians, and children alike. To maintain adequate control, national guidelines recommend monitoring of symptoms, identification of triggers, and regular use of appropriate medication, including inhaled corticosteroids (ICS) where applicable, plus use of asthma management plans (1). They also recommend that younger children are provided with parental support, while older adolescents may benefit from peer group support. Exercise is an important trigger of acute exacerbation of persistent asthma; however, NHLBI encourages children to participate in sports and physical

activity, with medication used to provide adequate control where necessary to prevent or abate exercise-induced symptoms. NHLBI guidelines clearly state that if asthma is properly managed, children should not have to limit their activity or avoid participating in sports at school because of their asthma, independent of the level of severity.

Children diagnosed with a chronic disease are reliant on their family for care (2). This is especially true for asthma where parental participation in disease management is essential to provide support and guidance for children. However, evidence indicates that parents overestimate

their children's level of asthma control (3). In a recent study, parents thought their children's asthma control was good, even though 50% of children were experiencing regular asthma symptoms, were using their reliever medication, had missed school, or required unscheduled visits to a health care provider because of their asthma (4). In addition, parents have previously been shown to underestimate their children's symptoms and use of health care services (5, 6). Adolescents have proven to be more reliable at accurately reporting medication use, exercise-induced asthma onset, quality of life, and symptoms than a parental proxy (7–9). Even in children previously hospitalized for an acute asthma exacerbation where parental awareness of disease management goals would be high, adherence to guideline recommendations for maintenance of asthma control was subsequently found to be poor (10).

To further investigate parent–child agreement about asthma, specifically in children aged 10–15, an age of transition between direct parental control of asthma treatment and adolescent management of their own condition, this study was designed to evaluate the level of agreement between parent and child pairs with respect to the frequency and control of asthma symptoms, medication use, trigger factors for asthma onset, and avoidance tactics to prevent symptoms.

Methods

A national sample of patients with asthma aged 4–18 was identified by systematically screening, through random-digit dialing, a national probability sample of 41,433 US households between late February and early-May 2004, and the full methods have been described previously (11). Children were classified as having asthma if they had ever been diagnosed by a physician as having asthma and either were taking medication for their asthma or had asthma symptoms in the past year. Interviews were conducted with the parent or caregiver most knowledgeable about the child with asthma, for children aged 4–15, while children aged 16–18 were interviewed directly about their asthma.

This study of parent–child agreement analyzed data from the subset of parents with children aged 10–15 from the full national sample described above, for whom an additional interview with the child was also conducted, yielding parent–child pairs ($n = 284$). Prior to interviewing these children, consent was obtained from the parent to answer an abbreviated version of the interviewer-administered questionnaire via telephone. The choice of age group 10–15 yr for

additional direct child/patient interviews was determined by (1) the requirements of phone interview, which was deemed too difficult for ages younger than 10 and (2) the concern that pre- and early adolescent ages are a time when children's behaviors become increasingly independent from parents' control/observation, often along with a decreased frequency of communication between parents and children.

Questionnaire

The abbreviated version of the questionnaire used for the supplemental interviews of 284 children aged 10–15 contained questions on socio-demographics, asthma triggers, symptoms in the past 4 wk, maintenance medication use in the past 4 wk, need for reliever medication ever, methods used to maintain asthma control including avoidance tactics, use of a written action plan ever, and physical activity limitations.

Analysis

All responses by parents and children were compared using the kappa statistic (κ). Kappa measures the strength of agreement of the row and column variables when there are two raters only (parent and child). The minimum value of kappa, when there is complete disagreement, is negative. When there is perfect agreement, all cell counts off the diagonal are 0 and kappa is 1. Kappa is zero when there is no more agreement than would be expected under independence of the row and column variables. Landis and Koch (12) give this interpretation of the range of kappa, which we have used in discussion: ≤ 0 poor; 0–0.2 slight; 0.21–0.4 fair; 0.41–0.6 moderate; 0.61–0.8 substantial and; 0.81–1 almost perfect.

Results

The demographic characteristics of the parents and children are presented in Table 1. The majority of parents or caregivers responding were female (88%). This sample of children with asthma was nearly balanced between ages 10–12 (45%) and 13–15 (55%), and 45% were female children. The distribution of race/ethnicity generally reflected the US national population, with the proportion of Hispanics slightly lower and the proportion of African-Americans slightly higher than national average. Children were most often insured via group plans (63%) or government plans like Medicaid (24%); no health insurance coverage for the child was

Table 1. Demographics of parent-child paired sample, Childhood Asthma in America 2004 Survey (n = 284)

	Parents	Children
Sex – female	88%	45%
Age	< 30 yr: 3% 30–39 yr: 43% 40+ yr: 53%	10–12 yr: 45% 13–15 yr: 55%
Race/ethnicity		
Black, non-Hispanic	NA	17%
Caucasian, non-Hispanic		62%
Caucasian, Hispanic		11%
Other		10%
Child's health insurance		
Employer/school/union-based plan	NA	63%
Self-insured, other		12%
Medicaid		24%
Other		5%
None		7%
Highest attained education (parent)		
Less than high school	1%	NA
High school degree	39%	
Some college	36%	
College graduate	24%	
Household smoking	37%	38%

reported by 7% of parents. Exposure to household smoking was reported by 38% of children.

Asthma trigger understanding varied between parents and their children as shown in Fig. 1. The top three triggers reported by both parents and children were weather, pollen, and exercise. Of these, exercise was reported less frequently by parents (35%) when compared to their children (58%) giving an only fair agreement (κ 0.23). When questioned about exercise, play, or other physical activity causing asthma symptoms in the last 4 wk (data not shown), nearly half of parents thought that this never occurred (47%), while only 31% of children stated this never happened (κ 0.06 – slight agreement). Thirteen percent of children reported daily asthma symptoms in

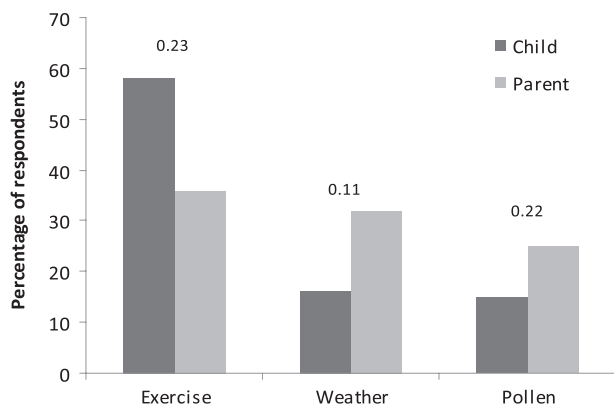


Fig. 1. Top three reported asthma triggers, as stated by parents and children. (Kappa is defined as: ≤ 0 poor; 0–0.2 slight; 0.2–0.4 fair; 0.4–0.6 moderate; 0.6–0.8 substantial; 0.8–1 almost perfect.)

response to physical activity, vs. only 8% of parents (κ 0.13 – slight agreement).

When asked what methods were used for the child to avoid having asthma symptoms, 63% of children reported avoiding exertion vs. 49% of parents (κ 0.004 – slight agreement), shown in Fig. 2. Other avoidance measures included staying inside, avoiding animals, avoiding stress, and minimizing exposure to (viral) illness. Caregivers consistently underreported all avoidance activities when compared to their children. Children and parents were asked to report prevalence of asthma symptoms in the past 4 wk as illustrated in Fig. 3. Children consistently reported higher prevalence of asthma symptoms in the past 4 wk compared with parents, and the agreement across all the questions was fair ($\kappa < 0.2$) between parents and children.

In addition to asthma triggers and symptoms, children with asthma and their parents were asked about asthma care, including medication use with a similar pattern of higher usage reported by parents. When asked if a written asthma action plan had ever been developed by a physician, 40% of parents stated 'yes' and 5% were 'unsure', but only 30% of children reported 'yes' and 28% of children were 'unsure' (κ 0.24 – fair agreement). When asked if maintenance medication (ICS, leukotriene receptor antagonists, ICS/LABA combination, cromolyn, or theophylline) had been used in the last 4 wk (Fig. 4), only 35% of children reported 'yes' vs. 44% of parents (κ 0.47 – moderate agreement). Any prior use of fast-acting reliever medication was reported by 67% of children and parents

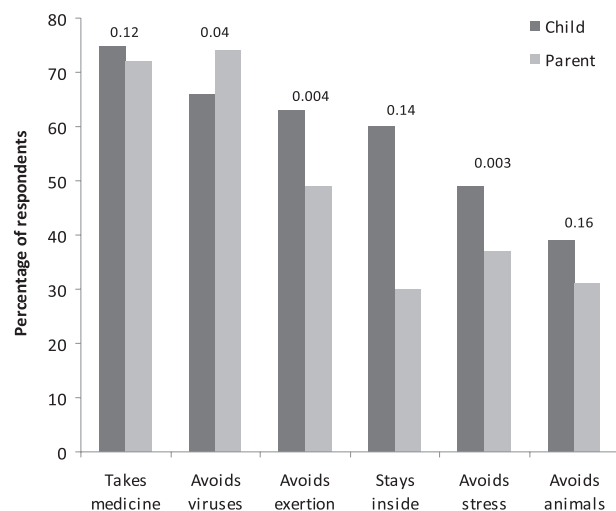


Fig. 2. Methods used to control asthma symptoms as reported by parents and children. (Kappa is defined as: ≤ 0 poor; 0–0.2 slight; 0.2–0.4 fair; 0.4–0.6 moderate; 0.6–0.8 substantial; 0.8–1 almost perfect.)

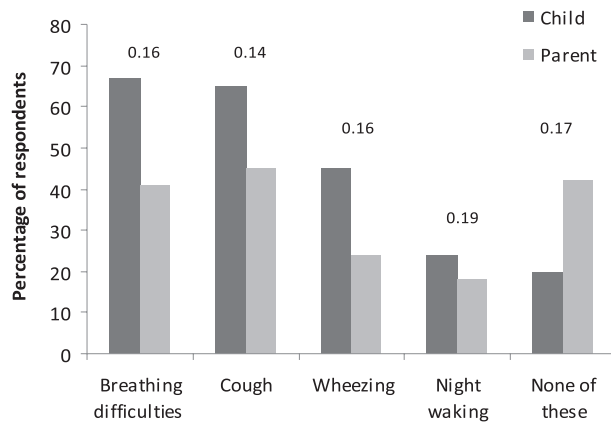


Fig. 3. Asthma symptoms in the past 4 wk as reported by parents and children. (Kappa is defined as: ≤ 0 poor; 0–0.2 slight; 0.2–0.4 fair; 0.4–0.6 moderate; 0.6–0.8 substantial; 0.8–1 almost perfect.)

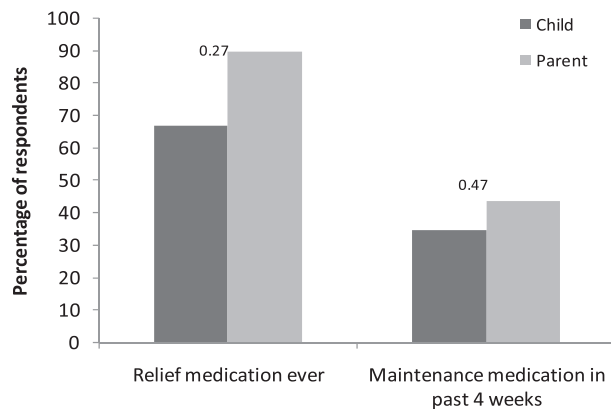


Fig. 4. Ever use of reliever and maintenance medication use in the past 4 wk, as reported by parents and children. (Kappa is defined as: ≤ 0 poor; 0–0.2 slight; 0.2–0.4 fair; 0.4–0.6 moderate; 0.6–0.8 substantial; 0.8–1 almost perfect.)

reported even higher use at 90% (κ 0.27 – fair agreement).

Discussion

This study highlights discrepancies between the reporting by children aged 10–15 with asthma and their parents with regard to the frequency and causes of asthma symptoms, medication use, and tactics to avoid asthma onset. Parents were less likely than children to report the impact of exercise on the child's asthma and generally underestimated the use of avoidance behaviors relative to the child's reporting. Parents additionally reported a lower prevalence of all asthma symptoms compared to that reported by children. Based on self-reported medication use, the majority of children (63%) failed to use regular

maintenance therapy, such as ICS. Ninety percent of parents actually thought their children had ever used a reliever medication, while only 67% of children recalled such use.

There are some limitations to this study inherent in the self-reported survey design. The study relied upon recall of symptoms, behaviors, and medication use, to reduce bias most questions only asked about activities that occurred in the last 4 wk. This is particularly relevant to use of drug therapy, as many children have intermittent asthma symptoms and subsequent use of controller therapy. In addition, no physician-reported data were available to confirm asthma diagnosis nor were pharmacy dispensing records available to confirm medication receipt or dates. While the distribution of race/ethnicity and the children's healthcare coverage generally resembled that of the US as a whole, it was somewhat surprising to note that this study population had household smoking rates higher than the US adult cigarette smoking prevalence rate (37% vs. 22.4%). This difference, however, may reflect the question wording regarding exposure from any member in the household smoking (parent, sibling, or other resident) rather than referring only to the individual parent responder (13). Finally, the survey sampling was limited to households with valid telephone numbers, not including cell phones. The Federal Communications Commission report on telephone subscribership near the time of this survey (2005) found that the telephone subscriber penetration rate in the United States was 94.0% (14). Despite these limitations, we believe that the survey findings are a reasonable representation of children with asthma in the United States.

These paired parent–child survey data show that many parents do not recognize that children restrict their exercise and physical activity to avoid triggering their asthma symptoms, nor exercise impacts upon their child's condition. NHLBI guidelines stipulate that all children with asthma should attempt usual activities including exercise with the aid of appropriate medication where necessary (1). The goal to achieve and maintain normal physical activity levels for children with asthma is particularly salient in times of increasing obesity prevalence in the USA, where all sections of the adolescent population are at risk but especially those who are from socially deprived or ethnic minority backgrounds (15). These data support previous findings from a UK study of 43 child/parent interviews, where parents' perception of asthma symptoms triggered by exercise or activity was unrelated to any physiological measure of airway

restriction such as FEV₁ and correlated weakly with Likert scores reported by children regarding symptom perception (9). The authors recommended that physicians obtain reports from the child rather than the parent when evaluating exercise-induced symptoms but warned that children also were limited in their accuracy of reporting. Better awareness by parents of the potential for exercise to trigger asthma symptoms that subsequent avoidance leads to lower levels of vigorous activity creating a potential illusion of control, and how to optimally medicate to allow participation in school sports, could all aid in increasing physical activity levels among children with asthma (16).

In this study, parents reported fewer asthma symptoms than their children. While parents may conceivably be unaware of asthma symptoms during the school day, in general parents have proven to be poor at estimating asthma control in their children, whatever their age, circumstance, or ethnicity (6, 17). In a previous US study, Dozier et al. (4) reported that 90% of 352 parents surveyed believed their children's asthma to be completely controlled even when 50% were missing school, experiencing symptoms, requiring emergency office visits, or regularly using a reliever. Dell et al. (5) also reported the same discrepancy of 55% of children being uncontrolled according to Canadian guideline standards, while their parents reported good control. In younger children under 10, parental proxy reporting of asthma symptoms may be slightly more accurate, but in children over 11 yr, Guyatt recommends relying on child report only (8).

While this study was not designed to investigate factors associated with definition of, or communication about symptoms, a study by Yoos et al. (3) of 228 children and their parents found that when describing asthma exacerbations, 48% of parents typically described non-standard as well as standard asthma symptoms, and 22% of parents never used any standard descriptions used by health professionals. Yoos found that parents particularly underreported cough, consistent with these survey results; only slight agreement between parents and children on the prevalence of the symptom (45% vs. 65%, respectively – κ 0.14) was observed. Braun-Farlander et al. (17) reported data from 14-yr-olds and their parents ($n = 1374$) who completed the International Study of Asthma and Allergy in Childhood (ISAAC) questionnaire and found factors associated with agreement between parental and adolescent reports of symptoms: questionnaires completed jointly by both parties, female adolescent, family history

of asthma reported, and higher parental education.

Use of maintenance medication had moderate agreement in this study, with children stating lower use of ICS in the past 4 wk than parents (35% vs. 44% – κ 0.46). The prevalence of controller therapy was consistent with data from a very large survey of 60,000 patients with asthma, where 40% of patients reported no recent use of controller therapy (18). These data suggest an increase in use compared to the initial 1998 Asthma in America survey, which reported 26.2% of children and adults with persistent asthma reported use of controller therapy in the previous 4 wk (19). To reduce the burden of asthma symptoms in children, barriers to use of regular maintenance medication like ICS need to be better understood and addressed. A recent study of 232 children aged 7–17 in the Netherlands offers results that translate into a simple action for parents; children positively reinforced to use ICS by their parents showed better adherence to medication than those who experienced less positive influences (20).

Overall, this analysis of survey responses from child and parent pairs found that parents underestimated tactics used by their children with asthma to avoid asthma triggers which included limiting exercise and physical activity. Relative to the child's self-report, parents tended to report a lower prevalence of asthma symptoms and were slightly discordant regarding medication use. These data suggest that increasing regular communication about asthma, particularly in the context of physical activity, between child, parent, and physician is warranted to improve asthma control and overall health.

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