

Parental understanding of wheeze and its impact on asthma prevalence estimates

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ABSTRACT: The epidemiology of wheeze in children, when assessed by questionnaires, is dependent on parents' understanding of the term "wheeze".

In a questionnaire survey of a random population sample of 4,236 children aged 6–10 yrs, parents' definition of wheeze was assessed. Predictors of a correct definition were determined and the potential impact of incorrect answers on prevalence estimates from the survey was assessed.

Current wheeze was reported by 13.2% of children. Overall, 83.5% of parents correctly identified "whistling or squeaking" as the definition of wheeze; the proportion was higher for parents reporting wheezy children (90.4%). Frequent attacks of reported wheeze (adjusted odds ratio (OR) 3.0), maternal history of asthma (OR 1.5) and maternal education (OR 1.5) were significantly associated with a correct answer, while the converse was found for South Asian ethnicity (OR 0.6), first language not English (OR 0.6) and living in a deprived neighbourhood (OR 0.6).

In summary, the present study showed that misunderstanding could lead to an important bias in assessing the prevalence of wheeze, resulting in an underestimation in children from South Asian and deprived family backgrounds. Prevalence estimates for the most severe categories of wheeze might be less affected by this bias and questionnaire surveys on wheeze should incorporate measures of parents' understanding of the term wheeze.

KEYWORDS: Childhood asthma, epidemiology, ethnic groups, questionnaires, social class, wheeze

ince the mid 1960s, the prevalence of childhood asthma has seen a high increase, levelled off and possibly begun to decline [1-4]. These changes have defied convincing explanation and the possibility that some of the time trends could be artefactual cannot be excluded. Current wheeze is conventionally used as a proxy marker to determine asthma prevalence in population surveys, with asthma being by far the most common cause of childhood wheeze beyond the neonatal period [5]. Alternative methods are unsatisfactory. Reported doctor's diagnosis is unreliable because diagnostic customs change with time [6] and objective measurements, such as lung function or bronchial responsiveness, are difficult to perform in large samples and results are not specific [7]. Even clinicians rely primarily upon a history of wheeze provided by parents for diagnosing and managing asthma.

Population estimates of asthma are thus directly dependent on parents' understanding of the term "wheeze". Recent studies of hospital-based

samples of children have challenged the validity of parent-reported wheeze, by showing that conceptual understanding of wheeze by parents differed from the definitions used by epidemiologists [8] and that parental understanding differed between ethnic groups [9]. To avoid such misunderstandings, it has been suggested that the term wheeze should be explicitly defined in questionnaire surveys [8]. Even so, it is not known whether parents adhere to the definition provided.

The present study utilised a recent questionnaire survey on respiratory symptoms in school children, which aimed to determine the scale, predictors and potential impact of parental misunderstanding of the term wheeze. Parents' knowledge of the term wheeze was investigated by assessing the description of the sound their child made when reported to have wheezed. The predictors of a correct definition were determined and the potential impact of incorrect answers on the results of the current survey was explored.

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METHODS

Population and study design

The current study was conducted among the participants of the second Leicestershire Children's Respiratory Cohort; details of the study have been published previously [1, 10-12]. Briefly, in April 1998, the Leicestershire Health Authority Child Health Database (Leicester, UK), which includes the birth notification with the mother's self-reported ethnic origin, religion, country of birth and language, was used to select an age-stratified random sample of white and South Asian (mother self-identified as Indian, Pakistani or Bangladeshi) children aged 1-5 yrs with complete birth records. South Asian children and those <2 yrs old were over-sampled to increase precision. In 1998, 2001 and 2003, the parents of these children received a postal questionnaire on respiratory symptoms. The response rate was 80% in 1998 and 49% (4,236 out of 8,700) in 2003; it was higher in white participants (3,197, 52%) than in South Asians (1,039, 40%). The current analysis is based on the 2003 questionnaires, when the children were aged 6-10 yrs old. The Leicestershire Health Authority Research Ethics Committee (Leicester, UK) approved the study.

Questionnaire

At the top of the four-page questionnaire [1, 13–15] a definition of wheeze was provided as "breathing that makes a highpitched whistling or squeaking sound from the chest, not the throat". Current wheeze was then assessed with a validated question: "wheezing or whistling in the chest in the last 12 months?" [5]. Parents reporting wheeze in their child were asked if the sound their child made when wheezing included the following: 1) squeaky or whistling noises; 2) wet, rattly noises; or 3) both whistling and rattly noises. For analysis, answers were categorised into two groups: those reporting whistling noises (with or without rattly noises) and those reporting only rattly noises.

At the end of the questionnaire, parents were asked if any of the following words meant the same as wheeze: rattly breathing; snoring; noises from the nose or throat during sleep; croup or stridor; whistling or squeaking noise in the chest; worrying dry cough; and moist or wet cough with phlegm. Every term could be answered separately as "yes", "no", or "don't know". For analysis, answers to these seven questions were summarised into three categories: 1) only whistling or squeaking noise accepted as a synonym for wheeze; 2) whistling or squeaking together with one or more other positive answer; and 3) whistling or squeaking not accepted as a synonym for wheeze.

The questionnaire also contained questions on severity and triggers of wheeze, environmental exposures, family history of atopy and socioeconomic conditions, measured at the individual level (duration of parental education) and area level (Townsend score, based on 1991 census data). Four families accepted an offer, written in Gujarati, Punjabi, Bengali and Urdu, of a phone interview in a South Asian language.

Analysis

There were <2% of answers missing for most questions on symptoms, and between 1.9 (whistling, squeaking noise) and 10.5% (croup/stridor) of answers missing in the questions on definition of wheeze. The answer to the question on noises

heard when the child had been wheezing was missing in 2.8% of current wheezers and 27.1% of ever wheezers. For the analysis, children whose parents did not reply to the question on the definition of wheeze (121) were excluded, leaving 4,115 children for further analysis. Missing and "don't know" answers in questions on symptoms were coded "no" when sensitivity analyses showed that this did not influence the magnitude or direction of the findings, or else were entered in the models as separate answer categories.

To investigate which factors were associated with the current outcome of interest, multivariate logistic regression models were used, with results expressed as odds ratios (OR) with 95% confidence intervals (95% CI). All variables that were associated with prevalence of wheeze (p<0.05) in univariate analysis plus age, sex and ethnicity, were kept in the multivariate models.

RESULTS

Definitions of wheeze chosen by parents

In 2003, "ever wheeze" was reported by parents of 1,204 out of 4,115 children (29.3%) and "current wheeze" (last 12 months) by parents of 544 children (13.2%). Of all 4,115 parents completing the questionnaire, 83.5% defined wheeze correctly as whistling or squeaking noise (fig. 1). However, a number of parents also accepted other sounds as synonyms for wheeze, most commonly rattly breathing (43.1%) and least frequently snoring (3.2%). In total, 30.7% of parents accepted only whistling, 52.8% chose whistling plus one or more other sound, and 16.5% did not include whistling at all. Parents of children with frequent wheezing attacks were most accurate (fig. 2).

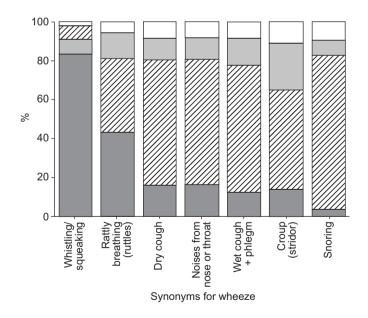


FIGURE 1. The proportion of parents agreeing that various respiratory noises are synonyms for "wheeze" in answer to the question, "Does the word "wheeze" mean the same as any of the following words?" Parents were allowed to tick more than one answer. **■**: yes; **■**: no; **[**2]: don't know; **□**: missing.

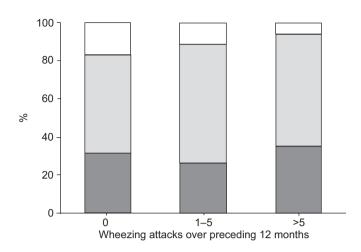


FIGURE 2. The proportion of parents approving the various descriptions by the number of wheezing attacks of their child during the past 12 months (I : only whistling; : whistling and other respiratory symptoms; : only other respiratory symptoms).

Predictors of a correct definition of wheeze

In a multivariate logistic regression, a strong positive association was found between a correct definition of wheeze (table 1), frequency of wheezing attacks in the past year and maternal wheeze/asthma. A correct answer was less likely in children of South Asian ethnicity, when the parents' first language was not English, if the questionnaire had not been completed by the mother or if the family lived in a deprived neighbourhood. While maternal education was positively associated with a correct definition, paternal education had no effect in the adjusted model. Stratified analysis for white and South Asian families showed a stronger effect of deprivation in South Asian (OR 0.34; 95% CI 0.20–0.56; p<0.001) than in white participants (OR 0.81; 95% CI 0.59–1.11; p=0.191; p-value for interaction=0.032).

Based on the fitted multivariate model, the likelihood of correctly including whistling in the definition of wheeze can be calculated. For instance, a white, well-educated, English-speaking mother living in a nondeprived neighbourhood, with a wheezing child and a personal history of asthma has a probability of 96% of knowing that wheeze means whistling. For a non English-speaking, South Asian father, from a deprived area and with no family history of asthma or wheeze, the figure would be 52%.

Description of sounds made by children reported to have wheezed

In total, 73.3% (688) of parents who reported that their child had ever wheezed said that their child made whistling noises when wheezing, and 26.7% (250) said their child made only rattly noises (table 2). Among current wheezers (544), the proportions were 76.1 (414) and 23.9% (130) respectively. Predictors of an accurate description of the noises made when wheezing (*i.e.* whistling) were: male sex, age >8 yrs, sleep disturbance due to wheeze, a doctor's diagnosis of asthma in the child, maternal asthma and South Asian ethnicity. Neither deprivation nor fathers' education affected the accuracy of reported wheeze (table 2).

Relationship between accuracy of parents' understanding and description of wheeze and reported wheeze in their children, in the last 12 months

Among the 13.2% of parents reporting current wheeze in their child (observed prevalence), 76.1% accurately described the noises their child made on these occasions as whistling or squeaking (corresponding to 10% true positives in the total population), while 23.9% described hearing only rattly noises and might be false positives (3.2% of the total population; table 3). Among the 86.8% of parents reporting no current wheeze in their child, 82.5% defined the term wheeze as a whistling or squeaking noise (71.6% true negatives), while 17.5% did not. This last group is probably heterogeneous and comprises both true negatives and potential false negatives, *i.e.* parents who may not report wheeze in their child because they misinterpret the term wheeze (15.2% potential false negatives). The proportion falling into this uncertain group is much higher among South Asian (28.3%) than white families (11.1%), and among deprived (22.8%) compared with affluent families (10.3%).

Table 4 summarises the impact of the data given in table 3 on the results of the questionnaire survey in which the overall prevalence of current wheeze was 13.2%. The data was examined using three different scenarios. Scenario A is very conservative and assumes that only those children whose parents report wheeze and correctly describe it as whistling (true positives, table 3) are true wheezers. Scenario B results in the highest estimate as it assumes that, in addition to children included in scenario A, all those whose parents do not report current wheeze but give an incorrect definition of wheeze are also true wheezers. This means that the number of truepositives (in table 3) and all potential false negatives (in table 3) were combined. Scenario C is intermediate and might be called realistic. It allows for the possibility that there are some true wheezers among those children whose parents do not report wheeze in their child and gave a wrong definition. An obvious choice is to assume the same prevalence of wheeze in this group, as there are true positives among children with parents who correctly defined wheeze. The lowest estimate (scenario A) would be a prevalence of 10% for current wheezers. The highest possible estimate (scenario B) would be 10+15.2%=25.2%, which is implausible. Scenario C would give an estimate for current wheeze of 11.9% for the total population. The fact that the number of potential false negatives was far larger in South Asian families and those from deprived neighbourhoods creates greater uncertainty and means that the crude prevalence data may considerably underestimate the true prevalence of wheeze in children from these backgrounds. Furthermore the prevalence ratio comparing South Asian and white families could be either 1.25 in scenario C or 0.99 in scenario A, compared with the crude prevalence ratio of 1.02 (13.5 out of 13.2%).

DISCUSSION

The present large population-based study showed that despite being given a description of wheeze in the questionnaire, 17% of families did not define wheeze as a whistling noise. Understanding of wheeze was better in parents with a personal history of asthma and in those reporting severe wheeze in their child, than in parents of South Asian ethnicity

	Interpretation of wheeze		Predictors of correct definition						
	Whistling	Other sounds	Age and sex adjusted			Fully adjusted ¹			
			OR	95% CI	p-value	OR	95% CI	p-value	
Subjects	3437 (83.5)	678 (16.5)							
Sex									
Female	1609 (84.1)	305 (15.9)	1			1			
Male	1828 (83.1)	373 (16.9)	0.93	0.79-1.10	0.381	0.88	0.74-1.05	0.163	
Age yrs									
<8	3015 (83.9)	578 (16.1)	1			1			
>8	422 (80.8)	100 (19.2)	0.81	0.64-1.02	0.076	0.98	0.76-1.27	0.901	
Ethnicity									
White	2755 (88.1)	371 (11.9)	1			1			
South Asian	682 (69.0)	307 (31.0)	0.30	0.25-0.36	< 0.001	0.56	0.42-0.75	< 0.001	
Language									
English	2881 (87.6)	409 (12.4)	1			1			
Other	541 (67.2)	264 (32.8)	0.29	0.24-0.35	< 0.001	0.64	0.48-0.85	0.002	
Person completing									
questionnaire									
Mother	2938 (85.8)	485 (14.2)	1			1			
Other	368 (69.6)	161 (30.4)	0.38	0.31-0.47	< 0.001	0.71	0.56-0.90	0.004	
Townsend index									
of deprivation									
Least-deprived third	1365 (89.3)	164 (10.7)	1			1			
Middle third	1141 (85.0)	201 (15.0)	0.68	0.55-0.85		0.82	0.65-1.03		
Most-deprived third	736 (74.0)	258 (26.0)	0.34	0.28-0.43	< 0.001	0.60	0.47-0.77	< 0.001	
Mother's education yrs									
<16	1407 (83.0)	289 (17.0)	1			1			
>16	1705 (87.1)	252 (12.9)	1.39	1.15–1.67	< 0.001	1.47	1.21-1.79	< 0.001	
Father had asthma/wheeze									
No asthma	2406 (83.2)	487 (16.8)	1			1			
Asthma	592 (89.3)	71 (10.7)	1.68	1.29–2.19	< 0.001	1.33	1.01–1.75	0.043	
Mother had asthma/wheeze									
No asthma	2454 (83.0)	502 (17.0)	1			1			
Asthma	610 (90.8)	62 (9.2)	2.02	1.53–2.67	< 0.001	1.54	1.15–2.05	0.004	
Wheezing attacks in the last									
12 months									
0	2909 (82.5)	618 (17.5)	1			1			
1–5	382 (88.4)	50 (11.6)	1.62	1.19–2.21		1.64	1.19–2.27		
>5	146 (93.6)	10(6.4)	3.10	1.62-5.92	< 0.001	3.04	1.56-5.93	<0.001	

TABLE 1 Prevalence and predictors of a correct definition of wheeze as a whistling sound in parents of 6–10-yr-old children[#]

Data are presented as n (%), unless otherwise stated. OR: odds ratio of a correct answer; 95% CI: 95% confidence interval. #: n=4,115; 1: data fully adjusted for all variables in the list, plus family size.

and in those living in adverse socioeconomic circumstances. When describing the sounds made by their own reportedly wheezy child, 27% of parents did not include whistling. These observations have general implications for the design and interpretation of epidemiological studies of wheeze and asthma, in relation to ethnicity, socioeconomic deprivation, sex and age and also for clinical practice.

Methodological issues

The strengths of the present study include the populationbased sampling strategy, large sample size and inclusion of South Asian families, the largest ethnic minority group in the UK. In contrast to reports on hospital-based samples, the results can be used to interpret the accuracy of questionnaire surveys in unselected population samples. A limitation of the study is the relatively low response rate and the possibility that there might have been a learning effect, as the families had received three questionnaires within 5 yrs. Also, it is important to note that a definition of wheeze was included in the questionnaire. These factors are likely to have led to an overestimation of the correct understanding of the word wheeze in the surveyed Leicestershire families. As written

TABLE 2

Prevalence and predictors of correct description by parents of the sound made by children who had ever wheezed#

	Sound of wheeze in child		Predictors of correct description						
	Whistling	Rattly sound alone	Age and sex adjusted			Fully adjusted ⁺			
			OR	95% CI	p-value	OR	95% CI	p-value	
Subjects	688 (73.3)	250 (26.7)							
Sex									
Female	281 (69.4)	124 (30.6)	1			1			
Male	407 (76.4)	126 (23.6)	1.43	1.07-1.92	0.016	1.38	1.02-1.85	0.036	
Age yrs									
< 8	609 (72.1)	236 (27.9)	1			1			
> 8	79 (84.9)	14 (15.1)	2.20	1.22-3.97	0.009	2.04	1.12–3.71	0.020	
Ethnicity									
White	524 (71.7)	207 (28.3)	1			1			
South Asian	164 (79.2)	43 (20.8)	1.46	1.00-2.12	0.048	1.52	1.03–2.23	0.033	
Mother had asthma/wheeze									
No asthma	402 (71.0)	164 (29.0)	1			1			
Asthma	191 (78.3)	53 (21.7)	1.46	1.02-2.09	0.037	1.45	1.01-1.09	0.046	
Diagnosis of asthma									
None	240 (67.6)	115 (32.4)	1			1			
Diagnosed	432 (76.7)	131 (23.3)	1.49	1.11-2.02	0.009	1.37	1.00-1.86	0.047	
Sleep disturbed by wheeze									
Not disturbed	393 (68.9)	177 (31.1)	1			1			
Disturbed	295 (80.2)	73 (19.8)	1.79	1.31–2.46	< 0.001	1.63	1.18–2.26	0.003	

Data are presented as n (%), unless otherwise stated. Analyses for language, person completing questionnaire, Townsend index of deprivation and mother's education showed no association with the sound made by children. OR: odds ratio of a correct answer; 95% CI: 95% confidence interval. #: n=938; [¶]: whether or not other terms included; ⁺; for all variables in the list.

questionnaires by their nature rely on both knowledge of the language and writing skills, the current results cannot be extrapolated to other survey methods such as video questionnaires.

Interpretation of findings

Of the parents reporting a wheezy child (13.2%), about a quarter did not describe having heard whistling or squeaking noises on the occasions their child had been wheezing. If it is assumed, very conservatively, that all of these are not true wheezers, the corrected prevalence estimate (scenario A) would be 10%. The proportion of such false positives did not vary much by ethnic or socioeconomic group.

Of the parents reporting no wheeze in their child (86.8%), a large proportion (17.5%, equalling 15.2% of the total population) did not know the correct definition of wheeze. Some of these might have given false-negative answers, either because the wheeze was inaudible or the whistling noise was actually heard by parents but not recognised as wheeze. As this group is relatively large, even a small proportion of false underreporting of wheeze could have a great effect on the total population estimate of wheeze. Questionnaire surveys are, therefore, more likely to underestimate the true prevalence of wheeze, not the converse.

The present findings have particular implications for interpretation of differences in prevalence between subpopulations, as summarised in table 4. With respect to ethnic groups, a recent systematic review concluded that the prevalence of wheeze and diagnosed asthma were lower in South Asian than white children in the UK, but that medical consultations and hospital admissions were more common [16]. Differences in understanding of the term wheeze by respondents from different ethnic groups could help explain this discrepancy. In the present survey, the crude prevalence of current wheeze was similar in South Asian and white children (13.5 compared with 13.2%). This was also true for the proportion of children for whom there was both reporting of current wheeze and an accurate description of noises heard during wheezing (10.1 and 10%, respectively). However, 28.3% of South Asian parents compared with 11.1% of white parents did not know that wheeze meant whistling. Due to this large, potentially falsenegative group, the true prevalence of wheeze in South Asian children, using the realistic scenario C could in fact be higher (14.2%) than in white children (11.4%). Similarly, the reported association between wheezing disease and deprivation in adults and schoolchildren [17-20] may be partly misleading, since the accuracy with which wheeze was reported in the current study was lower in families living in deprived circumstances. Using scenario C, the proportion of current wheeze in the lowest (least deprived) and highest (most deprived) thirds of the Townsend score would be 10.8 and 16.1%, respectively, which increases the difference in prevalence between socioeconomic groups compared with the

TABLE 3

Relationship in the whole population between accuracy of parents' understanding of wheeze and reported wheeze in their children in the last 12 months

			Ethnic group		Townsend index [#]			
	Category	All children	White	South Asian	Least-deprived third	Middle third	Most-deprived third	
Subjects		4115 (100)	3126 (100)	989 (100)	1529 (100)	1342 (100)	994 (100)	
Reported current wheeze		544 (13.2)	411 (13.2)	133 (13.5)	198 (12.9)	160 (11.9)	157 (15.8)	
Accurate description	TP	414 (10.0)	315 (10.1)	99 (10.0)	147 (9.6)	123 (9.2)	122 (12.3)	
Inaccurate description	FP	130 (3.2)	96 (3.1)	34 (3.5)	51 (3.3)	37(2.7)	35 (3.5)	
No reported current wheeze		3571 (86.8)	2715 (86.9)	856 (86.5)	1331 (87.1)	1182 (88.1)	837 (84.2)	
Correct definition	TN	2945 (71.6)	2369 (75.8)	576 (58.2)	1174 (76.8)	995 (74.2)	610 (61.4)	
Incorrect definition	PFN	626 (15.2)	346 (11.1)	280 (28.3)	157 (10.3)	187 (13.9)	227 (22.8)	

Data are presented as n (%). TP: true positive; FP: false positive; TN: true negative; PFN: potential false negative. #: the Townsend index is missing for 250 individuals.

TABLE 4	Potential impact of incorrect answers on the results of this prevalence survey by three different scenarios [#]						
	Observe	d Pi	Prevalence by scenario				
	prevalen	ce A	В	с			
All children	13.2	10.0	25.2	11.9			
By ethnic group							
White	13.2	10.1	21.2	11.4			
South Asian	13.5	10.0	38.3	14.2			
By Townsend index							
Least-depriv	red third 12.9	9.6	19.9	10.8			
Middle third	11.9	9.2	23.1	10.7			
Most-deprive	ed third 15.8	12.3	35.1	16.1			

Data are presented as %. Scenario A: assumes 0% true prevalence in those who incorrectly understood wheeze but did not report wheezing children (prevalence=true-positives (TP)/n). Scenario B: assumes 100% true prevalence in those who incorrectly understood wheeze but did not report wheezing children (prevalence=(TP+potential false negatives (PFN)/n). Scenario C: assumes that the prevalence calculated in those who correctly defined wheeze applies to those who understood wheeze incorrectly and did not report wheeze (prevalence = (TP/n)+PFN × (TP/(TP + true-negatives))/n). #: assuming different proportions of false-negative reports in children of parents who incorrectly understood wheeze.

crude prevalence estimates (12.9 *versus* 15.8%). The most reassuring findings of the present survey were that understanding of the term wheeze and accuracy of symptom reporting rose with increasing frequency and severity of wheeze. Therefore, more stringent definitions of wheeze (severe wheeze) should be routinely used as additional outcome measures in epidemiological surveys in order to confirm their main findings.

Comparison with other studies

The present general population-based results confirm and supplement findings from hospital-based populations, which

showed limited understanding of the term wheeze by parents [8, 9, 21]. It has been suggested that a video questionnaire might avoid the problem of misunderstandings inherent to written questionnaires. The prevalence of wheeze as assessed by video questionnaires is lower than if assessed by written questionnaires, and the correlation between the two methods is not very good [22]. However, video questionnaires were not better predictors of objective traits associated with asthma than written questionnaires [22].

Implications for future research and clinical practice

Future studies should interpret crude prevalence estimates of wheeze with more caution, especially when using the data to compare different ethnic groups and social classes. The main analyses, especially if the outcome of interest is current wheeze, should be confirmed by a secondary analysis including only those with more severe wheezing. The precision of prevalence and incidence estimates might be improved by inclusion of questions which determine parents' understanding of the term wheeze and descriptions of the sounds heard on the occasions when the child is reported to have been wheezing. Objective measurements (such as bronchial responsiveness or allergy tests) should be used to validate findings in subgroups of the population.

Another finding that might have implications for research and clinical practice is that significantly more parents of young females reported rattly noises in their child during a wheezing attack, compared to young males. This might imply differences in symptom presentation in young females and males, and could explain some of the apparent underdiagnosis and undertreatment of young females [10, 23, 24]. For clinicians, who rely largely on parental reports of symptoms for managing wheezing children, it is essential to explore parental understanding of the term wheeze rather than accepting reports at face value.

In conclusion, the present study showed that the interpretation of questionnaire studies in childhood wheezing disorders is hampered by variation of parents' understanding and interpretation of the term wheeze. This uncertainty should be accounted for by both clinicians and researchers, especially when investigating sociodemographic and ethnic variations in asthma prevalence. Prevalence estimates for the most severe categories of wheeze might be less affected by this bias and questionnaire surveys on wheeze should incorporate measures of parents' understanding of the term wheeze.

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