Parent misperception of control in childhood/adolescent asthma: The Room

to Breathe Survey

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ABSTRACT [198 words]

To determine how often asthma control is achieved in children and adolescents, and how

asthma affects the parents' and children's daily lives, interviews including the childhood

asthma control test (C-ACT) were conducted with 1284 parents of asthmatic children (aged 4-

15 years), as well as with the children themselves (aged 8-15 yrs, n=943), in Canada, Greece,

Hungary, The Netherlands, South Africa, and the United Kingdom.

Parents reported mild asthma attacks at least weekly in 11% of children, and serious attacks

(requiring oral corticosteroids or hospitalization) at least annually in 35%. Although 73% of

parents described their child's asthma as mild or intermittent, 40% of children/adolescents

had C-ACT scores ≤19, indicating inadequate control and only 14.7% achieved complete

GINA-defined control and just 9.2% achieved SIGN/BTS-defined control. Guideline-defined

asthma control was significantly less common than well-controlled asthma using the C-ACT

(p<0.001). Asthma restricted child's activities in 39% of families, and caused lifestyle

changes in 70%.

Complete asthma control is uncommon in children worldwide. Guideline-defined control

measures appear to be more stringent than those defined by C-ACT or families. Overall

parents underestimate their child's asthma severity and overestimate asthma control. This is a

major potential barrier to successful asthma treatment in children.

Key words: adolescents; asthma; children; control; parents; survey

Abbreviations used:

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AIRE: Asthma Insights and Reality

BTS: British Thoracic Society

C-ACT: Childhood-Asthma Control Test

CI: Confidence interval

GINA: Global Initiative for Asthma

ICS: Inhaled corticosteroids

LABA: Long-acting β₂ agonists

N/A: Not applicable

NA: Not available

OR: Odds ratio

SE: Standard error

SIGN: Scottish Intercollegiate Guidelines Network

INTRODUCTION

Global and national guidelines for asthma management have evolved considerably during the last two decades; from treatment recommendations based on the level of asthma severity to the current emphasis on achieving full asthma control.^{1,2} Asthma control is defined as the extent to which the various manifestations of asthma are reduced or removed by treatment.³ Poor assessment of asthma control results in suboptimal treatment; good asthma control is associated with improved quality of life and reduced health care utilization.⁴⁻⁷

Reliable assessment of asthma control in children/adolescents is essential to enable effective care via the tailoring of therapy to improve outcomes. Despite widespread availability of effective therapies, asthma control often falls short of guideline standards; this may be due to overestimation of asthma control by both physicians and parents coupled with low expectations of achievable control. Suboptimal asthma control in children and adolescents has been indicated by several surveys. Filo-14 For example, parents from the UK, Germany, and Spain considered their child's/adolescent's asthma well-controlled but also reported visiting the emergency department within the previous 3 months. It would seem that parents of children/adolescents with asthma perceive significant levels of symptoms, lifestyle restriction, and reliance on reliever medication as good control.

More than a decade ago, the Asthma Insights and Reality (AIRE) survey described international variations in the severity, control, and management of asthma in 3153 children/adolescents in 29 countries across North America, Europe, and Asia. Results indicated that patient perception of asthma control did not correspond with their symptom severity; approximately half of patients reporting severe persistent symptoms also considered

their asthma to be completely or well controlled.¹⁶ As guidelines have since been revised considerably, with increased emphasis on the importance of gaining and maintaining control, we wanted to re-evaluate parental and child's perspectives on childhood/adolescent asthma and identify barriers to achievement of asthma control in an international survey.

The Room to Breathe survey was a large international study in which both parents and children/adolescents were interviewed to establish their assessment of asthma severity and control, and how asthma affected their lives. In addition, the survey compared guideline-defined asthma control measures to that assessed with the validated Childhood-Asthma Control Test (C-ACT).¹⁷

METHODS

The Room to Breathe questionnaire was developed by the authors in collaboration with a medical communications company (FD Santé, London, UK), and a market research agency (ICM Research, London, UK). The study was funded by Nycomed (Zurich, Switzerland). Editorial control remained with the study authors. The survey was conducted between November 25, 2008 and January 9, 2009. The UK National Research Ethics Service advised that ethical review by a Research Ethics Committee was not required.

Selection of subjects

Respondents were selected randomly from the general population; a sample of children/adolescents with physician-diagnosed asthma was identified by systematic screening of 17,383 households by telephone in five countries (Canada, Greece, Hungary, The Netherlands, and the United Kingdom) and face-to-face in South Africa (due to local regulations). The telephone sampling technique is described in Appendix 1 of the Online Repository. The respondent had to have a child/adolescent aged 4-15 years diagnosed with asthma who was currently using asthma medication within their household, and be the parent or primary caregiver.

If more than one child/adolescent with asthma was present in the household, the parent was asked only to refer to one (selected by the interviewer according to age quotas) when answering the questionnaire. Parents were interviewed first, followed by the child/adolescent with asthma, if aged ≥8 years (i.e., those considered able to formulate valid opinions/responses). Respondents were assured of the voluntary nature of the survey and the confidentiality of all survey responses.

Interviews

Interviews were conducted by experienced interviewers in the respondent's mother tongue, using a structured questionnaire that contained a maximum of 78 questions and was divided into three sections (screening/profiling; parental responses; child responses). Parental responses were followed by children's responses in all cases. Appendix 2 of the Online Repository contains a complete copy of the questionnaire (English version). The English version of the questionnaire was translated and back-translated into Dutch, Greek, and Hungarian by translators with experience of health surveys.

In order to obtain a validated measure of asthma control, this survey incorporated the validated 7-item (four child and three caregiver items) C-ACT. Asthma control was also assessed based on GINA and the British Thoracic Society (BTS)/Scottish Intercollegiate Guidelines Network (SIGN) guidelines. GINA criteria for controlled asthma include all of the following: no daytime symptoms (twice or less/week), no limitation of activities, no nocturnal symptoms or awakening, no need for reliever/rescue treatment (twice or less/week), and no exacerbations. BTS/SIGN guideline control was achieved if there were: no daytime symptoms, no night-time awakening due to asthma, no need for rescue medication, no exacerbations, no limitations on activities including exercise. 20

Data management and analysis

Data were collected by ICM Research and its partners in participating countries. Data analysis was performed by the authors. Differences between normally distributed means were tested by Student's t test, and differences between proportions by chi-squared test. Agreement between different methods of assessing asthma control and severity was measured by Cohen's kappa statistic. *P* values < .05 were considered statistically significant. All analyses were performed using STATA (release 10, StataCorp, College Station, Texas, USA).

RESULTS

Parents and children/adolescents

Overall, 1284 families were interviewed. Parent and child characteristics are shown in Table 1. Most interviews were conducted with mothers; the majority of children with asthma were male.

Asthma symptoms

Parents were asked to describe how frequently their child experienced mild and serious asthma attacks; these data are presented in online Table I (see online Appendix). Parents reported that their children had mild asthma attacks at least weekly in more than 10% of cases; only one in six children had a mild asthma attack once a year or less often (online Table I). Severe asthma attacks, requiring oral corticosteroids or hospitalization, were reported at least once a year for 34.9% of children/adolescents. Frequent occurrence of such severe attacks (at least once a month) were much more common in South Africa (27.5% of children) than in other countries (mean 3.4%, p<0.0001) (online Table I). Parents were also asked to record nocturnal awakenings and use of reliever medication for their children (figure 1). During the last 4 weeks, more than half of the children had awakened at night at least once due to their asthma, and reliever medication had been used by two-thirds of children.

Asthma severity as rated by parents

Parents were asked how they would describe the child's asthma. They were given 4 possible options. Of the 1284 respondents, 424 (33%) described their child's asthma as intermittent, 512 (39.9%) described it as mild, 271 (21.1%) as moderate and just 77 (6%) as severe.

Asthma control

Asthma control as assessed using C-ACT, GINA, and BTS criteria, is presented in Table 2. Irrespective of the control measure used, poor asthma control was common. A C-ACT score of < 19 (indicating inadequate asthma control) was recorded for 336 children (40%). Similarly, 85% of children/adolescents had incompletely controlled asthma as defined by GINA and 91% as defined by the SIGN/BTS guidelines. Guideline-defined asthma control was a significantly more stringent measure of control than the C-ACT score (p < .001). The number of uncontrolled GINA items varied significantly by country (online table II). In accordance with the higher frequency of serious asthma attacks in South Africa (online Table I), well-controlled asthma (0 or 1 uncontrolled GINA items) was less common in this country (12.5%) than in the other countries (44.3%, p < 0.0001).

The relationship between parental and children's perception of asthma and GINA-defined asthma control is summarized in online Table III. Whilst poor asthma control (3 or more GINA uncontrolled items) was more common in children whose asthma was described as moderate (149/271, 55%) or severe by their parents (66/77, 86%) it also occurred in a considerable proportion of children whose parents described their asthma as mild (127/511, 25%) or intermittent (109/424, 26%). Children's self-report of asthma severity showed better concordance with guideline-defined asthma control. Almost all children (38/42) who described their asthma as 'very bad' had poor asthma control (3 or more

GINA uncontrolled items). However, such bad asthma control was also found in children who graded their own asthma as 'not too bad' (129/393, 32.8%) or "I only get it now and again" (66/367, 17.7%) (online table III). Agreement between parents and children's scores was only poor with a kappa score of 0.119.

In accordance with guidelines children with poorer asthma control were more likely to be prescribed more asthma medication. Thus, those children with incomplete asthma control were 1.3 to 2.2 times more likely to be prescribed an inhaled corticosteroid (ICS) than bronchodilators alone (GINA-defined [odds ratio (OR) 1.83; 95% confidence interval (CI) 1.32-2.53; P = .0001]; BTS/SIGN-defined [OR 2.23; 95% CI 1.50-3.33; P < .0001]; C-ACT defined [OR 1.30; 95% CI 0.96-1.77; P = .078]). Long-acting β_2 agonists (LABA) prescription was even more consistently associated with incomplete control by any measure. Those children with incomplete asthma control were approximately 1.7 to 2.4 times more likely to be prescribed a LABA (GINA-defined, OR 2.38; 95% CI 1.48-3.97; P = .0002; BTS/SIGN-defined, OR 2.05; 95% CI 1.16-3.86; P = .01; C-ACT defined, OR 1.66; 95% CI 1.20-2.30; P = .0002.

A detailed breakdown of GINA control within the cohort is presented in online table IV. In decreasing order of frequency parents reported exacerbations (60.8%), nighttime symptoms (54.3%), limitation of activity (47.5%), reliever use more than twice per week (21.8%) and daytime symptoms (13.2%).

Impact on family life and parental concerns

Childhood/adolescent asthma had a substantial impact on family life. 42% of parents reported taking time off work; 40% regularly missed sleep; 37% devoted more time and attention to the child with asthma than to others in the household; 27% reported that they had abstained from engaging in activities or family events believing that these were unsuitable for individuals with asthma; and 24% spent more time with the child/adolescent at home as their movements were restricted. Most parents (70%) reported that they had implemented lifestyle changes to reduce the asthma-related risks to their child, and 39% thought that their child/adolescent's asthma limited participation in various activities. This did not appear to be influenced by age (P = 0.821) with similar proportions reporting a change in each age group. However, there was a clear influence of overall control, families with children with 3 or more uncontrolled GINA items being more likely to report undertaking lifestyle changes (78.9% versus 65.4% (P < .001)).

At diagnosis, 78% of parents were worried about their child's general health and welfare.

Whilst by the time of the interview, this had decreased significantly to 38% (P < .001)

certain common concerns persisted. 57% of parents worried their child/adolescent would have an attack when they or their partner were not around, 41% worried that their child might run out of medication while out of the house, and 31% believed that their child/adolescent would not be able to lead a 'normal' life.

DISCUSSION

The results of this international survey show that parents overestimate their child's asthma <u>control</u>. The majority of parents considered their child's asthma to be mild or intermittent; a very low proportion of parents actually used the term 'severe'. However, the C-ACT showed that almost half of children/adolescents had scores of ≤19, suggesting inadequately controlled asthma. Asthma control as assessed GINA or BTS/SIGN guidelines was even worse (Table 2). These results either indicate a reluctance of parents to concede that their child's asthma is inadequately controlled and that this situation requires action, or suggest that parents fail to recognize poor control because children's symptoms may be difficult to detect. However, the latter explanation is at odds with recent studies which conclude that caregivers can make reliable assessments of asthma control even in preschool children.²¹ The disparity between the perceived level of asthma severity by parents and the actual reported symptoms supports previously reported work in this field. 11,13,22 These data, taken in conjunction with previous reports, suggest that parents seem to maintain a belief that even mild asthma will remain symptomatic despite treatment with ICS, placing an important obstacle in the path of guideline-defined control for children.^{23,24} Our recruitment strategies were designed to minimise possible bias introduced by source of recruitment. For instance, recruitment from hospital clinics might have tended to increase the severity of asthma reported. Random dialling was believed to give us the highest likelihood of identifying families with children whose experiences of asthma were typical of the general population. Due to legal considerations in South Africa, a telephone-based recruitment strategy was impossible. This, along with different economic conditions and

access to health care between the countries, may have led to the inclusion of more severely affected children in the South African cohort (online Tables I and II). Another explanation for the difference in asthma control between South African children and those in other countries may be the limited access to health care and underinsurance issues in the former country. Studies in inner-city African-American children in the United States who also suffer from limited health insurance and access to health care confirm that asthma control in such subjects is poor.²⁵⁻²⁸ The gender distribution and self-assessed asthma severity of the children in this study was comparable with that of previous studies such as AIRE.¹⁶ The lack of asthma control in children and adolescents has been highlighted previously.^{5,9} Poorly controlled asthma represents a heavy socioeconomic burden on society. ^{29,30} Poor adherence to treatment guidelines in young people with asthma has been related to their parents lacking sufficient knowledge about the illness and is also influenced by parental beliefs (poor expectations) and concerns about treatment.³¹⁻³³ GINA guidelines indicate that asthma self-management education is imperative for providing patients with the skills required to control asthma and improve outcomes in their children¹⁹ and other studies have also highlighted the need for a good educational program. 34-37 It is unlikely that the poor level of asthma control in most participants in this survey was due to physician under-treatment, because those with the most poorly controlled asthma were most likely to report receiving a combination of different asthma controller medications. However, we cannot exclude poor inhaler technique, poor adherence or 'corticosteroidphobia' as a cause for persistent poor control. Indeed when we asked parents of children receiving ICS those who self-reported 'concerns about steroid medication' were more likely to have a child with very poor control (3 or more GINA uncontrolled items) (OR 1.65, 95% CI 1.23-2.23, p=0.0006). This would

suggest that steroid phobia may be an important contributor to control and is consistent with recent qualitative research.²³

Although the concept of asthma control has become a key issue in international asthma guidelines, there is no consensus on how to assess it. The results of this study show that different methods to assess asthma control (C-ACT, BTS/SIGN, GINA) yield different levels of asthma control. Guideline-defined asthma control was found to be less common than well-controlled asthma using the C-ACT. Using the C-ACT may therefore underestimate asthma control in real life. Clinicians should also be aware that simply asking parents or children to assess the current state of their asthma is likely to yield an overly optimistic picture of asthma control. We, therefore, encourage clinicians caring for children with asthma to carefully check in each follow-up visit whether GINA controlled items have been truly attained, and to interview parents on the limitations they impose on their child's activities because of their asthma.

We acknowledge several important limitations of the Room to Breathe survey. The large scale of the survey and the use of telephone interviews in most countries meant it was not possible to apply objective measures such as lung function. C-ACT has only been validated in children aged 4-11 years and with face-to-face interviews. The authors acknowledge that telephone responses may not be identical to those received during face-to-face interview. Whilst scores of <=19 indicate inadequately controlled asthma the sensitivity and specificity of C-ACT are considerably less than 100% (sensitivity 74%, specificity 68%). This will, of course lead to both under and overestimation of control as sensitivity and specificity are lower than 100%. We therefore chose to present data for an intermediate area of C-ACT score (20-21) as a separate value. This division of the C-ACT score was not undertaken by its authors (17).

Moreover we have applied it to children up to 15 years of age. Nonetheless, there is a degree of face validity for these approaches, as there is a strong inverse correlation between C-ACT scores and other measures of control (GINA and SIGN/BTS (P < 0.001) and despite the size of the sample C-ACT does not significantly differ by age grouping (P = 0.197). In our cohort children with C-ACT scores of 22 or greater had a mean (SD) number of 1.10 (0.89) GINA uncontrolled items, children with C-ACT scores of 20-21 had a mean (SD) number of 2.04 (0.89) GINA uncontrolled items and those with C-ACT scores of <=19 had a mean of 3.12 (1.05) GINA uncontrolled items.

In our analyses no weighting was given to the individual components of GINA or SIGN/BTS control. Thus a child who had used a reliever more than twice per week (>10/28 days) would be considered as uncontrolled as a child who used their reliever many times a day. Moreover, the receipt of an oral steroid burst is highly dependent upon a number of physician, parent and child factors which might not indicate overall control. Future studies including lung function measurements would be especially helpful in clarifying the relationships between individual control items. Remote measurement of lung function measurement may greatly assist this type of data collection.

The strengths of the Room to Breathe study include the large sample size, having yielded over 1000 responses from parents regarding their child's asthma, and the international setting. Furthermore, we believe the relative anonymity offered by telephone interviews are likely to result in honest responses to questions.

Asthma control guidelines have changed considerably since the AIRE study was

published; 16 the modern goal of asthma therapy is to achieve asthma control by reducing

current impairment and future risk. Although there are numerous effective treatment

options available, the data collected in this study indicate that current

paediatric/adolescent asthma management remains suboptimal. The study has also

highlighted that parents are relatively poor discriminators of their child's asthma severity,

tending to underestimate severity, providing a major barrier to maintenance of adequate

treatment. It is, therefore, important for healthcare professionals to ensure not only that

adequate education is delivered to the primary caregivers of children/adolescents with

asthma³⁸ but that the child remains central to any discussions regarding control in the

clinic.

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FIG 1. Parent-reported incidence of their child's nocturnal awakenings and use of reliever medication during the last 4 weeks.

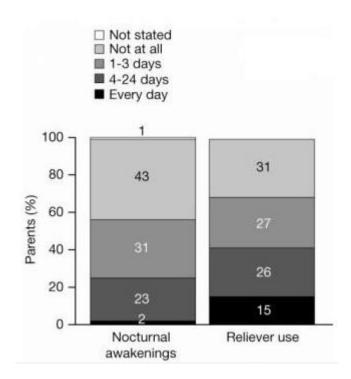


TABLE 1. Baseline demographics and characteristics of parents and the children/adolescents about whom they were interviewed(parent report and n=1,284 throughout except for C-ACT data)

	Total	Canada	Greece	Hungary	The Netherlands	South Africa	United Kingdom
Number of parents interviewed, n	1284	228	225	225	206	200	200
Gender of parent, % female	87	81 ($P = .007$)	85 ($P = .512$)	98 $(P = .001)$	83 ($P = .090$)	91 $(P = .084)$	82 ($P = .034$)
Age distribution of parent, %							
18-24 years	1	1	_	1	_	3	_
25-34 years	23	25	10	40	14	28	23
35-44 years	53	50	64	49	53	44	55
45-54 years	20	21	25	9	31	15	21
55-64 years	2	3	2	_	1	7	2
≥65 years	_	_	_	_	_	3	_
Gender of child/adolescent,	40	39	34	38	41	54	38
% female		(P = .713)	(P = .049)	(P = .441)	(P = .951)	(P = .001)	(P = .592)
Age distribution of child/ adolescent, %							
4-7 years	27	30	22	22	26	25	35
8-10 years	26	25	22	22 29	26 25	25 25	33 29
11-13 years	26	23	22	35	28	23 26	29
14-15 years	20	23 21	34	33 14	28	24	15
	22	∠1	34	14	21	24	13
Infant mortality rate (deaths per 100,000)	NA	5.0	4.0	6.0	4.0	46.0	4.4
Smoker in household, %	44	36	33	53	32	48	31

Reported smoking within house, %	9	11	11	4	8	9	11
C-ACT score (n=844), mean (SD)	19.8 (4.3)	19.4 (4.3)	20.6 (4.3)	20.1 (4.3)	20.1 (3.7)	17.7 (4.1)	20.8 (4.4)
Inhaled corticosteroid use, %	67	75	58	82	72	41	69
Inhaled long acting $\beta 2$ agonist use, %	22	15	11	40	27	24	16
Leukotriene receptor antagonist use, %	15	13	7	51	9	2	6

P values represent each country compared with the rest of the countries combined.

TABLE 2. Asthma control as measured by C-ACT, GINA, and BTS criteria

	GINA ^a		BTS ^b	Total (%)	
C-ACT score	Controlled	Uncontrolled	Controlled	Uncontrolled	
≤12 (inadequate asthma control)	0 (0%)	58 (100%)	0 (0%)	58 (100%)	58 (7%)
13-19 (inadequate asthma control)	7 (3%)	271 (97%)	1 (0.4%)	277 (99.6%)	278 (33%)
20-21 (incomplete asthma control)	13 (7%)	168 (93%)	3 (2%)	178 (98%)	181 (21%)
≥22 (well controlled asthma)	102 (31%)	225 (69%)	78 (24%)	249 (76%)	327 (39%)
Total (%)	122 (14%)	722 (86%)	82 (10%)	762 (90%)	844 (100%)

BTS: British Thoracic Society; C-ACT: Childhood-Asthma Control Test; GINA: Global Initiative for Asthma; SIGN: Scottish Intercollegiate Guidelines Network.

^aGINA criteria for controlled asthma include all of the following: 1. no daytime symptoms (twice or less/week), 2. no limitation of activities, 3. no nocturnal symptoms or awakening, 4. no need for reliever/rescue treatment (twice or less/week), 5. no exacerbations.

^bBTS/SIGN control include all of the following: 1. no daytime symptoms, 2. no night-time awakening due to asthma, 3. no need for rescue medication, 4. no exacerbations, 5. no limitations on activities.