



Parent misperception of control in childhood/adolescent asthma: the Room to Breathe survey

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ABSTRACT: The aim of our study was to determine how often asthma control is achieved in children and adolescents, and how asthma affects parents' and children's daily lives.

Interviews, including the childhood asthma control test (C-ACT), were conducted with 1,284 parents of asthmatic children (aged 4–15 yrs), as well as with the children themselves (aged 8–15 yrs; n=943), in Canada, Greece, Hungary, the Netherlands, South Africa and the UK.

Parents reported mild asthma attacks at least weekly in 11% of children, and serious attacks (requiring oral corticosteroids or hospitalisation) 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 Global Initiative for Asthma (GINA)-defined control and just 9.2% achieved Scottish Intercollegiate Guidelines Network (SIGN)/British Thoracic Society (BTS)-defined control. Guideline-defined asthma control was significantly less common than well-controlled asthma using the C-ACT ($p < 0.001$). Asthma restricted the 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.

KEYWORDS: Adolescents, asthma, children, control, parents, survey

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 healthcare utilisation [4–7].

Reliable assessment of asthma control in children/adolescents is essential to enable effective care *via* the tailoring of therapy to improve outcomes [8]. 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 [9]. Suboptimal asthma control in children and adolescents has been indicated by several surveys [5, 10–14]. For example, parents from the UK, Germany and Spain considered their child's/adolescent's asthma to be well controlled, but also reported visiting the emergency department within the previous 3 months [14]. 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 [15].

More than a decade ago, the Asthma Insights and Reality (AIRE) survey described international variations in the severity, control and management of asthma in 3,153 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

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asthma to be either 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 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 with those assessed using 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). 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 UK) and face-to-face in South Africa (due to local regulations). The telephone sampling technique is described in Appendix 1 of the online supplementary material. The respondent had to have a child/adolescent aged 4–15 yrs 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 yrs (*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 and child responses). Parental responses were followed by children's responses in all cases. Appendix 2 of the online supplementary material 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 seven-item (four child and

three caregiver items) C-ACT [17]. Asthma control was also assessed based on Global Initiative for Asthma (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 (two or fewer per week), no limitation of activities, no nocturnal symptoms or awakening, no need for reliever/rescue treatment (twice or less/week), and no exacerbations [18]. 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, and no limitations on activities including exercise [19].

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 using unpaired t-test and differences between proportions by the Chi-squared test. Agreement between different methods of assessing asthma control and severity was measured by Cohen's kappa statistic. *p*-values < 0.05 were considered statistically significant. All analyses were performed using STATA (release 10; StataCorp, College Station, TX, USA).

RESULTS

Parents and children/adolescents

Overall, 1,284 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 supplementary material). Parents reported that their children had mild asthma attacks at least weekly in $>10\%$ of cases; only one in six children had a mild asthma attack one or fewer times per year (online supplementary material; table I). Severe asthma attacks, requiring oral corticosteroids or hospitalisation, 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 supplementary material; table I). Parents were also asked to record nocturnal awakenings and use of reliever medication for their children (fig. 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 their child's asthma. They were given four possible options. Of the 1,284 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

TABLE 1 Baseline demographics and characteristics of parents and the children/adolescents about whom they were interviewed[#]

	Total	Canada	Greece	Hungary	The Netherlands	South Africa	UK
Parents interviewed n	1284	228	225	225	206	200	200
Female parents	87	81	85	98	83	91	82
p-value [†]		0.007	0.512	0.001	0.090	0.084	0.034
Age distribution of parent yrs							
18–24	1	1		1		3	
25–34	23	25	10	40	14	28	23
35–44	53	50	64	49	53	44	55
45–54	20	21	25	9	31	15	21
55–64	2	3	2		1	7	2
≥65						3	
Female children/adolescents	40	39	34	38	41	54	38
p-value [†]		0.713	0.049	0.441	0.951	0.001	0.592
Age distribution of child/adolescent yrs							
4–7	27	30	22	22	26	25	35
8–10	26	25	22	29	25	25	29
11–13	26	23	22	35	28	26	22
14–15	22	21	34	14	21	24	15
Infant mortality rate deaths per 100000	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[‡]	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 LABA use	22	15	11	40	27	24	16
Leukotriene receptor antagonist use	15	13	7	51	9	2	6

Data are presented as % or mean ±SD, unless otherwise stated. C-ACT: Childhood-Asthma Control Test; LABA: long-acting β₂-agonist; NA: not available. [#]: parent report and n=1,284 throughout except for C-ACT data; [†]: p-values represent each country compared with the rest of the countries combined; [‡]: n=844.

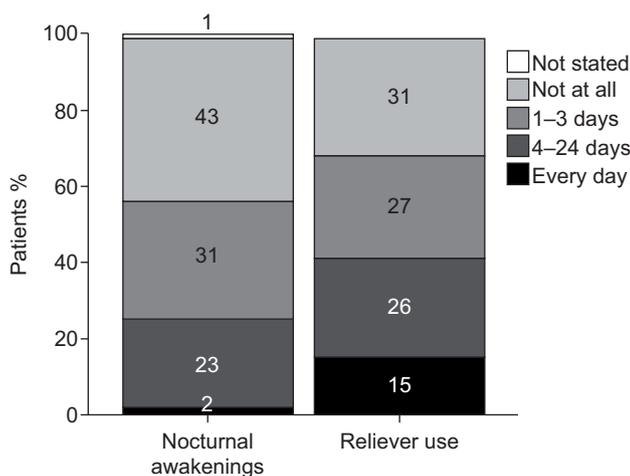


FIGURE 1. Parent-reported incidence of their child's nocturnal awakenings and use of reliever medication during the last 4 weeks.

(indicating inadequate asthma control) was recorded for 336 (40%) children. 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 ($p<0.001$). The number of uncontrolled GINA items varied significantly by country (online supplementary material; table II). In accordance with the higher frequency of serious asthma attacks in South Africa (online supplementary material; table I), well-controlled asthma (one or fewer 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 summarised in table III of the online supplementary material. Whilst poor asthma control (three or more GINA-uncontrolled items) was more common in children whose asthma was described as moderate (149 out of 271, 55%) or severe by their parents (66 out of 77, 86%), it also occurred in a considerable proportion of children whose parents described their asthma as mild (127 out

TABLE 2 Asthma control as measured by Childhood-Asthma Control Test (C-ACT), Global Initiative for Asthma (GINA) and British Thoracic Society (BTS) criteria

C-ACT score	GINA [#]		BTS [†]		Total
	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)

Data are presented as n (%). [#]: GINA criteria for controlled asthma include all of the following: 1) no daytime symptoms (twice or less per week), 2) no limitation of activities, 3) no nocturnal symptoms or awakening, 4) no need for reliever/rescue treatment (twice or less/week) and 5) no exacerbations. [†]: BTS/Scottish Intercollegiate Guidelines Network 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 and 5) no limitations on activities.

of 511, 25%) or intermittent (109 out of 424, 26%). Children's self-reporting of asthma severity showed better concordance with guideline-defined asthma control. Almost all children (38 out of 42) who described their asthma as "very bad" had poor asthma control (three 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 out of 393, 32.8%) or "I only get it now and again" (66 out of 367, 17.7%) (online supplementary material; 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 1.3–2.2 times more likely to be prescribed an inhaled corticosteroid (ICS) than bronchodilators alone (GINA-defined (OR 1.83 (95% CI 1.32–2.53); $p=0.0001$); BTS/SIGN-defined (OR 2.23 (95% CI 1.50–3.33); $p<0.0001$); C-ACT defined (OR 1.30 (95% CI 0.96–1.77); $p=0.078$)). Long-acting β_2 -agonist (LABA) prescription was even more consistently associated with incomplete control by any measure. Those children with incomplete asthma control were ~1.7–2.4 times more likely to be prescribed a LABA (GINA-defined (OR 2.38 (95% CI 1.48–3.97); $p=0.0002$); BTS/SIGN-defined (OR 2.05 (95% CI 1.16–3.86); $p=0.01$); C-ACT defined (OR 1.66 (95% CI 1.20–2.30); $p=0.002$)).

A detailed breakdown of GINA control within the cohort is presented in table IV of the online supplementary material. In decreasing order of frequency, parents reported exacerbations (60.8%), night-time 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 three or more uncontrolled GINA items being more likely to report undertaking lifestyle changes (78.9% versus 65.4%; $p<0.001$).

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% ($p<0.001$), certain common concerns persisted. 57% of parents worried that their child/adolescent would have an attack when they or their partner was 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 children's asthma control. 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 recognise 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 [20]. The disparity between the level of asthma severity perceived by parents and the actual reported symptoms supports previously reported work in this field [11, 13, 21]. 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 [22, 23].

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 healthcare between the countries, may have led to the inclusion of more severely affected children in the South African cohort (online supplementary material; 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 healthcare and underinsurance issues in the former country. Studies in inner-city African-American children in the USA who also suffer from limited health insurance and access to healthcare confirm that asthma control in such subjects is poor [24–27]. The sex 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 [28, 29]. 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 [30–32]. 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 children [18] and other studies have also highlighted the need for a good educational programme [33–36]. 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 (three 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 [22].

Although the concept of asthma control has become a key issue in international asthma guidelines, there is no consensus on how to assess it [8]. The results of this study show that different methods to assess asthma control (C-ACT, BTS/SIGN and 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 yrs 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% and specificity 68%) [17]. This will, of course, lead to both under- and overestimation of control, as sensitivity and specificity are $<100\%$. 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 ≤ 15 yrs 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 had a mean \pm SD of 1.10 ± 0.89 GINA-uncontrolled items, children with C-ACT scores of 20–21 had 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 out of 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-related 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 $>1,000$ responses from parents regarding their child’s asthma and the international setting. Furthermore, we believe the relative anonymity offered by telephone interviews is 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, and 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 asthma [37], but also

that the child remains central to any discussions regarding control in the clinic.

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STATEMENT OF INTEREST

Statements of interest for all authors and for the study itself can be found at www.erj.ersjournals.com/site/misc/statements.xhtml

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