

# The burden of paediatric asthma is higher than health professionals think: results from the Asthma In Real Life (AIR) study

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## Abstract

**Aim:** To assess perceptions of children with asthma, parents of children with asthma and Health Care Professionals (HCPs) of asthma symptoms, lifestyle impairment, perceived control and treatment effects using the dataset provided within the AIR study.<sup>1</sup>

**Method:** Questionnaire based survey of 687 parents of children aged 0-14 with asthma, 579 children aged 9-14 with asthma and HCPs treating asthma (401 practice nurses and 809 GPs).

**Results:** Symptom frequency in patients was higher than expected by HCPs, as was reliever use - with 45% of patients using reliever

three times per day. 65% described their asthma as "well controlled" yet of these: 37% had difficulty breathing, 34% nocturnal waking, 29% dry cough and 29% ability to talk adversely affected by asthma at least weekly.

**Conclusions:** HCPs underestimate asthma symptom prevalence and lifestyle limitation. Many children with asthma and parents appear to perceive significant levels of symptoms, lifestyle restriction and reliance on reliever medication as good control. This perception needs to be challenged if progress is to be made in improving patient outcomes.

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## Introduction

The aims of asthma treatment in children are to maintain patients as symptom-free as possible, minimise exacerbations, relief treatment usage activity and lifestyle limitation whilst maintaining or improving lung function.<sup>2,3</sup>

Occurrence of asthma symptoms despite treatment has been blamed on inadequate or improper prescribing or poor adherence with preventive, anti-inflammatory therapies. Although preventive therapy prescribing has increased greatly over the last few years<sup>4</sup> this may not solve all the problems of asthma as additional strategies may be needed to help overcome poor adherence which is present in up to 50% of patients with asthma.<sup>5</sup>

Several studies have shown asthma symptoms are common in children,<sup>6-8</sup> but there is much less work exploring the impact of asthma on their daily lives and virtually none comparing this with HCPs' perceptions. This study explores the impact of asthma in children - in terms of symptoms, impact on normal activities and perceptions of asthma control. It also assesses whether asthma symptoms might be related to reported under-use of preventive therapies.

Finally, the study compared what aspects of asthma children and their parents rated as being important, with factors considered important by HCPs. The great majority of patients with asthma are managed entirely within general practice, so practice nurses and GPs attitudes were investigated.

## Methods

The data for this study was obtained from an analysis of the paediatric subset of the AIR study,<sup>1</sup> during August and September 1997. Over 90% of primary care prescriptions in the UK are dispensed by a community pharmacist. All children aged 8 to 14 and parents of younger children or parents who were

unaccompanied by their children were asked to complete questionnaires on-site about their asthma treatment and symptoms when they collected asthma medication from 800 randomly selected pharmacies throughout the United Kingdom. Others collecting scripts were excluded from the study, as were children whose parents stated the medication was not for asthma. Children over the age of 8 were allowed to complete the questionnaire with parental assistance. Recruitment was undertaken in pharmacies rather than GP surgeries and over a three month period to minimise severity bias.

Following pilot studies, questionnaires were developed by the authors for completion by parents and children containing questions addressing the following issues:

- Asthma duration
- Current treatment
- How often inhalers used
- Which inhaler they felt helped most and perceived benefits
- Whether they deliberately administer or take less preventer treatment than advised
- Frequency and presence of asthma symptoms: dry cough, tight chest, nocturnal waking due to asthma and difficulty talking due to asthma
- Open questions to find out difficulties and limitations experienced on 'bad asthma days'
- Perceived overall asthma control

Asthma therapy was classified into relievers (short-acting  $\beta$ -2-agonists), preventers (inhaled steroids and cromoglycate) and controllers (long-acting  $\beta$ -2-agonists and xanthines). Leukotriene antagonists were not included as this study was undertaken prior to their launch in the UK.

The health professional study was based on telephone interviews with 401 practice nurses involved in asthma management and face-to-face interviews with 809 GPs. GPs were sourced using Taylor Nelson Sofres weekly GP omnibus, Omnimed, which carries

out regular face-to-face interviews with GPs. GPs and practice nurses were chosen to be a nationally representative sample and were asked about their perceptions of patients' asthma symptoms and their beliefs about asthma treatment. Questions also covered how they considered asthma affected patients' lifestyles and how they defined 'bad asthma days'.

**Results**

**Patients**

A total of 579 children aged 8 to 14 years, agreed to complete questionnaires with parental assistance as required. The parents of a further 687 children aged 0-14 years, also agreed to complete the questionnaire to give a total of 1266 responses. Non-response rates are unknown given the nature of pharmacy practice. 51.7% of these children were male. Most children had an asthma diagnosis for between 1-5 years, apart from very young study participants.

**Asthma treatment**

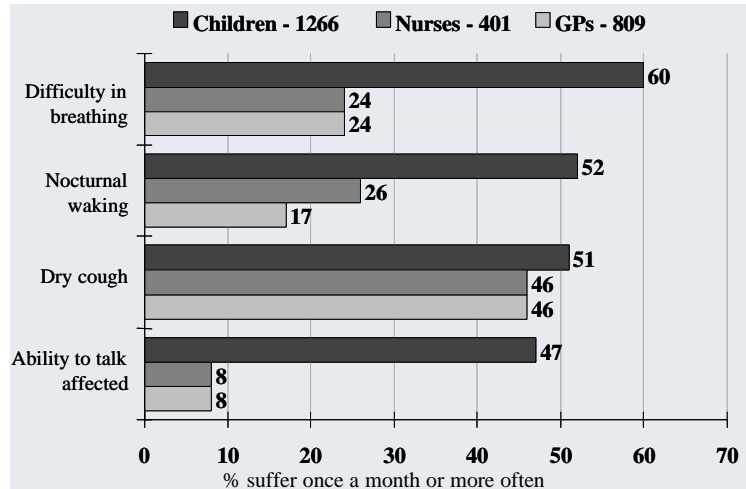
Parents and patients stated that 25% received a reliever without a preventer (33% of under 5s and 24% of those 5 and over); 61% received a preventer without additional controller therapy (56% < 5 years; 62% =5 years); 12% received a preventer and additional controller treatment (7% <5 years, 13% =5 years). 2% of patients received unclassifiable therapy such as theophylline as sole therapy.

**Asthma symptoms**

Reported symptom frequency was similar across age groups and whether reported by parents or children and is presented in table 1. 60% reported difficulty in breathing at least once a month, with similar proportions suffering nocturnal waking (52%), dry cough (51%); 47% said that their ability to talk was affected by asthma at least once a month. 29% of children suffered dry cough or found their ability to talk affected by their asthma at least once a week, while 34% reported nocturnal waking and 37% had difficulty in breathing.

HCPs suggested lower rates of these symptoms than reported by patients. GPs and practice nurses

	≥ Daily %	≥ Weekly %	≥ Monthly %	Never %	Not Stated %
<b>Asthma wakes you/them in the night</b>	4.50	34.0	52.0	16.0	0.0
<b>Dry cough</b>	6.56	29.0	51.0	12.0	5.0
<b>Difficulty in breathing</b>	7.50	37.0	60.0	9.0	5.0
<b>Asthma affects ability to talk</b>	5.45	29.0	47.0	23.0	6.0



**Figure 1: Symptom prevalence at least once a month - comparison of statements of children and parents with views of health care professionals**

estimated difficulty in breathing affected 24% of patients at least monthly and that ability to talk would be affected in only 8% of patients. Practice Nurses were slightly more aware of the level of nocturnal waking, estimating it affected 26% of patients, compared to GPs who thought that it affected 17%. Both groups had a more accurate estimation of dry cough, estimating that it affected 46% of patients at least monthly (figure 1).

**Perception of inhaler usage and benefit**

Parents and children with asthma perceived that reliever medication was the most helpful treatment - 65% of children and 56% of parents stated that reliever inhalers helped asthma the most. Approximately one-quarter (22%) of children and parents considered preventer inhalers to be most helpful.

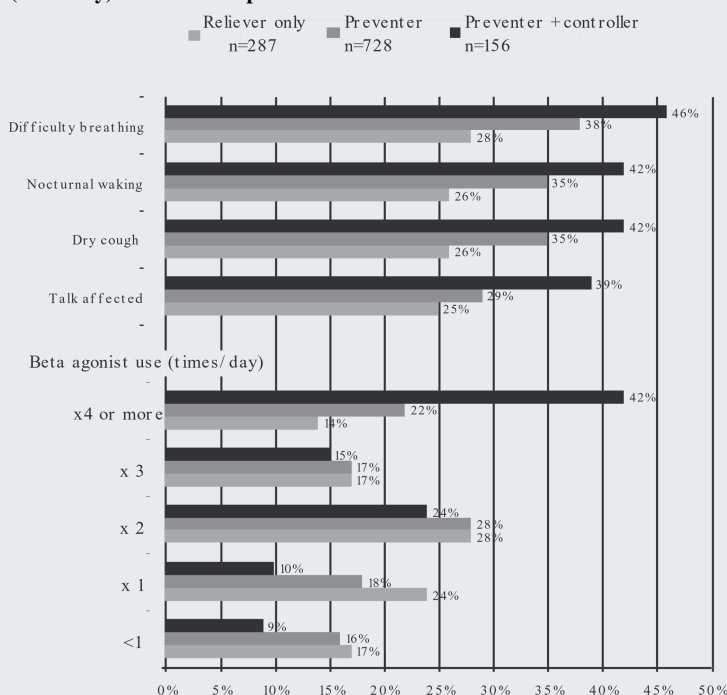
HCPs' perception of preventer inhaler benefit when complied with was at variance with that reported by parents and children - with 52% of patients/parents stating when they complied with their preventer they still suffered symptoms (practice nurses - 19%; GPs - 20%).

More respondents (42%) admitted taking less preventer therapy than recommended and this proportion was more than HCPs thought (practice nurses - 30%; GPs - 36%).

HCPs also underestimated how many children felt they needed their reliever inhaler more than the guideline aim of less than daily2 (50% of children vs. practice nurses 27% and GPs 30%).

Mean daily reliever usage was reported at 2.9 times a day. Results showed greater β-2-agonist use was not associated with lack of preventer medication. In fact, children who used a preventer reporting using β-2-agonists

**Figure 2, At least weekly asthma symptoms and average stated reliever use (times/day) vs. treatment prescribed**



**Table 2. Patients' asthma symptoms versus perceived level of asthma control**

	Total Base: 1266	Completely Base: 201	Well Base: 825	Not well Base: 206	Not at all well Base: 15
<b>Difficulty in breathing</b>	60	36	59	87	93
<b>Nocturnal Waking</b>	52	27	51	77	100
<b>Dry cough</b>	51	35	50	71	87
<b>Ability to talk affected</b>	47	24	46	74	80
	<i>% of patients experiencing it once a month or more often</i>				

**Table 3. Relief treatment usage vs. stated asthma control**

	Total n=1266 %	Completely n=201 %	Well n=825 %	Not well n=206 %	Not at all well n=15 %
<b>x4 or more</b>	23	15	20	38	46
<b>x3</b>	17	9	17	23	15
<b>x2</b>	28	23	30	23	23
<b>x1</b>	18	24	19	12	15
<b>None</b>	15	30	14	5	0

slightly more frequently than those receiving reliever therapy alone. These rates were further increased in those taking a preventer plus additional controller therapy (figure 2).

Similarly increasing severity of asthma symptoms showed a pattern of increased use of preventer therapy and other controller therapy (figure 2).

**Impact of asthma on activities**

Half of the children (51%) reported they could not do everything those without asthma could - HCPs expectations were at slight variance (practice nurses - 38%; GPs - 41%). Underestimation of specific things children were prevented from doing was greater - for example 53% of children reported having to avoid contact with animals, while practice nurses thought this would affect 29% and GPs 25%.

The free text section where patients described the impact of a 'bad asthma day' showed the commonest problem was inability to participate in sport, to play games or take part in physical education, reported by 27% of children; playing with friends 22%, running or jogging 17%; going to school 12% and disturbed sleep 6%. GPs and practice nurses reported symptoms predominantly rather than activities in response to this question.

**Perceived asthma control**

81% of respondents described their own, or their child's asthma as well controlled or completely controlled with 16% considering asthma not well controlled. However, symptoms and relief treatment usage appeared poorly related to how well patients considered their asthma was controlled. Of the 825 children who considered their asthma well controlled, 59% suffered difficulty in breathing at least once a month, 51% nocturnal waking, 50% dry cough and 46% their ability to talk affected (table 2). Similarly reliever usage bore little relationship to perceived asthma control with 15% of those stating they were completely controlled using relief treatment 4 or more times a day (table 3).

**Discussion**

One potential drawback of this study is that the rate of non-responders is unknown although the age distribution of responders prescribing patterns and relief treatment usage were consistent with that found in the authors' practices<sup>1</sup> and outcomes reported in other surveys.<sup>6-9</sup> It is also not possible to assess the comparative effects of the telephone versus face to face interviews utilised in this study. Furthermore, without direct knowledge of the information provided to patients by their physician we cannot explain the instances of conflicting results from patients and health professionals. For example, the comparatively high rate of reported avoidance of animals by the children to those predicted by the health professionals may be explained by instructions to the children to avoid contact. Whilst quantitative comparisons between the views of HCPs and patients or parents should therefore be viewed with caution other findings regarding patients views on treatment, symptoms and asthma control are important even if they apply to a substantial subset of patients.

This community-based study of children with asthma revealed a high level of asthma symptoms and impact on normal activities, despite apparently appropriate prescribing consistent with several previous surveys of patients with asthma.<sup>6-9</sup>

Patients generally considered that they had good asthma control despite levels of symptoms and reliever use that suggested the contrary. Results suggest many children required excessive  $\beta$ -2-agonist relief treatment, with many using them at least four times daily, while guidelines suggest that they should ideally be needed less than daily.<sup>2</sup> This did not appear to be due to lack of prescribing of preventer therapy. In fact, children taking preventer medication, or taking a preventer plus an additional type of asthma therapy, tended to use more  $\beta$ -2-agonists and suffer more symptoms than those on only reliever therapy. This indicates that there is a lack of asthma control in children of all levels of asthma severity that is more marked in those with more severe disease.<sup>10</sup> Interestingly, many patients reported that even when they adhered fully with preventer therapy it did not fully control their asthma. Whilst adherence was not fully formally assessed in the study, many patients admitted to taking less preventer therapy than recommended and this perception may be one reason for this. HCPs appeared to underestimate how frequently children were using reliever inhalers.

One positive point was both children and HCPs reported cough as a common asthma symptom, as a previous study suggested this symptom was often not reported by children with asthma.<sup>10</sup> However, it is of concern that health professionals generally underestimated the prevalence of asthma symptoms.

It is of note that this study revealed a far higher percentage of children using preventer treatment (60%) than a similar European wide study where the percentage was between 26 and 34% although recruitment methods were different.<sup>11</sup> The figure in this study is consistent with that seen in UK prescribing databases and suggest guideline advice on use of anti-inflammatory agents is being followed.

The findings support differences found in other work between what HCPs and patients perceive of as 'health'. HCPs tend to define 'health' on a medical model, as an absence of illness or symptoms. In contrast, patients tend to focus on concepts such as 'being able' or 'looking after yourself'.<sup>12</sup> The danger of this has been emphasised by a recent study that revealed some children with asthma at risk for poor self-concept associated with negative attitudes towards their illness.<sup>13</sup>

This study taken in conjunction with other published work in this area suggests a number of ways asthma outcomes might be improved.

Firstly, we need to be careful not to accept parents or children's statements that their asthma is well controlled as this study shows that whilst superficially it may be so in reality if we probe deeper, asthma control in many children will be revealed to be relatively poor.

Secondly, it may be necessary to redefine what is meant by asthma control for children and their parents. It might be helpful to ask children about their ability to take part in activities that they want to include in their daily lives, such as exercise and playing with friends, in order to more accurately define and assess asthma control i.e. what does your asthma prevent you from doing.

Finally, there seems to be a gap in communication between patients and HCPs as demonstrated by apparent underestimation of asthma symptom prevalence and reliever medication usage by HCPs. Children with asthma also defined 'bad asthma days' differently to HCPs. GPs and practice nurses focused on symptoms, while patients focused on activity limitation. Communication may improve if HCPs take more account of outcomes that are important and relevant to patients. Peak flow rates and inhaler use are useful indicators, but a patient-focused approach should additionally include measures such as limitation of activities. If consultations offer the prospects of achieving changes that are meaningful to patients, the therapeutic partnership might become more effective. ■

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