RESEARCH PAPER

Adherence to national guidelines for children with asthma at primary health centres in Sweden: potential for improvement

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Abstract

Background: Although asthma is the most common chronic paediatric disease in Western Europe, the extent of adherence to guidelines for primary care management of paediatric asthma remains unclear.

Aims: To evaluate adherence to national guidelines for primary care management of children with asthma.

Methods: This survey involved 18 primary healthcare centres in Stockholm, Sweden. The medical records of 647 children aged 6 months to 16 years with a diagnosis of asthma, obstructive bronchitis, or cough were selected and scrutinised. 223 children with obstructive bronchitis or cough not fulfilling the evidence-based criteria for asthma were excluded, yielding a total of 424 subjects. Documentation of the most important indicators of quality as stipulated in national guidelines (i.e., tobacco smoke, spirometry, pharmacological treatment, patient education, and demonstration of inhalation technique) was examined.

Results: Only 22% (n=49) of the children 6 years of age or older had ever undergone a spirometry test, but the frequency was greater when patients had access to an asthma nurse (p=0.003). Although 58% (n=246) of the total study population were treated with inhaled steroids, documented patient education and demonstration of inhalation technique was present in 14% (n=59). Exposure to tobacco smoke was documented in 14% (n=58).

Conclusions: This study reveals a substantial gap between the actual care provided for paediatric asthma and the recommendations formulated in national guidelines.

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Introduction

Asthma and other allergic diseases represent the largest group of

chronic paediatric diseases in many Western countries.¹ In Sweden, 8–10% of children and young people suffer from asthma.² Most children with asthma are treated in primary care or paediatric outpatient clinics. The severity of asthma varies greatly and there may

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be considerable morbidity, especially during periods when symptoms are uncontrolled.³ However, with high-quality healthcare providing optimal treatment, most children with asthma can live an active and normal life.⁴ The goal for asthma treatment is that every individual, as far as possible, should live without symptoms and exacerbations.^{5,6} To achieve this goal, children with asthma must get support to manage their disease.⁵⁻¹⁰

Primary care is the basis of the Swedish healthcare system and is expected to satisfy most patients' needs for medical treatment, care, prevention, and rehabilitation. When more specialised care is required, patients are cared for in hospital-based clinics. Some Primary Healthcare Centres (PHC) have asthma teams including general practitioners (GPs) and a specialised nurse with specific expertise in asthma and allergy, and often also chronic obstructive pulmonary disease (COPD).⁷

The national guidelines for the care and treatment of asthma and COPD are formulated by the National Board of Health and Welfare and include proposed measurable indicators of quality.^{5,8} These are available in both paper and web-based formats.

In many cases the control of asthma in children is poor and only a small fraction achieve the desirable level of control set up as a goal by the Global Initiative for Asthma (GINA).^{9,10} Factors reported to facilitate asthma control include the use of a spirometer and access to a specialised asthma nurse.^{11,12} Having access to an asthma nurse has been shown to increase patients' knowledge, improve asthma care, and reduce costs.¹³

In several fields of medicine, many patients fail to achieve the goals set by evidence-based guidelines¹⁴⁻¹⁷ and, for adults with asthma, adherence to guidelines in primary care has been reported to be poor.¹⁸⁻²⁰ However, the management of asthma and adherence to guidelines for children with this disease by healthcare professionals is unclear. The aim of this study was to evaluate this adherence.

Methods

Acquiring clinical data

This cross-sectional survey included 18 PHCs in Stockholm, Sweden and involved two steps. In 2006 the medical records of 81 children aged 6 months to 16 years diagnosed with asthma (ICD code J45) were scrutinised at four PHCs (Figure 1). The four PHCs were selected so that two of them had an asthma nurse specialised in asthma care. Subsequently, in 2007, nurses and general practitioners from 20 PHCs in the northern region of Stockholm were invited to a seminar on paediatric asthma where those attending were asked to participate in the present investigation, of which 14 accepted. In order to obtain patients ranging from 6 months to 16 years in age, the medical records of all children at the total 18 PHCs were divided into four groups on the basis of age. Five children from each group were randomly selected from diagnostics lists.

The medical records of children aged 6 months to 16 years ($n=566$) diagnosed with asthma ($n=281$), obstructive bronchitis (ICD code J22) or cough (ICD code R09) ($n=285$) at these 14 PHCs between January 2007 to February 2008 were reviewed.

Figure 1. Trial profile: patient selection, inclusion and final study population

Categorisation of data

All of the medical records ($n=647$) were scrutinised in their entirety (i.e. not only the index visits over 12 months) by two specially trained nurses. De-identified data were marked with a random ID number for each patient and each PHC. The presence of asthma was defined either as a medical diagnosis in the medical record (ISD-10 code J45) or as a recorded diagnosis of obstructive bronchitis (ISD-10 code J22) or cough (ISD-10 code R09) assigned in the medical record, but fulfilling the evidence-based criteria for a diagnosis of asthma as proposed by the Swedish National Board of Health and Welfare in Sweden.⁶ Subsequently, children with a diagnosis of obstructive bronchitis or cough who did not fulfil these latter criteria of asthma ($n=223$) were excluded, leaving a final study population of 424 children (Figure 1).

A template of predefined indicators of quality of relevance to asthma care was constructed, including information on patient history, clinical examination, as well as pharmacological and non-pharmacological treatment. In addition, the template included information concerning performance of spirometry tests and of pharmacological treatment during the most recent 12-month period (index visits period).

Table 1. Indicators of quality prioritised in the national guidelines* for paediatric asthma care at primary health centres (PHC)

Indicators of structure	Indicators of process	Indicators of results
Patient history		
Allergic co-morbidity	Appropriate documentation	Correct diagnosis
Family history of allergic disease	Appropriate documentation	Correct diagnosis
Exposure to tobacco smoke	Appropriate documentation	Avoidance of exacerbation (primary and secondary prevention)
Furry pets at home	Appropriate documentation	Avoidance of exacerbation (primary and secondary prevention)
Indoor environment	Appropriate documentation	Avoidance of exacerbation (primary and secondary prevention)
Clinical examination		
Spirometry test at >6 yrs of age	Performed	Correct diagnosis and monitoring
Peak expiratory flow (PEF) at >4 yrs of age	Performed	Correct diagnosis, monitoring and improved self-care
Allergy tests	Performed	Avoidance of exacerbation (primary and secondary prevention)
Pharmacological treatment**		
Inhaled steroids	Prescribed	Correct treatment, reduced morbidity and improved quality of life
Short acting β_2 -agonist	Prescribed	Removal of obstruction
Acute nebulisation	Performed at the PHC	Removal of obstruction and reduction of anxiety and morbidity
Non-pharmacological treatment		
Patient education	Documentation of such education being provided	Improved adherence and self-control
Planned follow-up	Documentation of such a plan	Improved asthma control

*National Board of Health and Welfare in Sweden (2004) for guidelines of asthma care and care of chronic obstructive pulmonary disease.

**Medical Products Agency – Sweden for pharmacological treatment of asthma (2007).

Quality was assessed on the basis of indicators of structure, process, and result, in the prioritised areas proposed in the national guidelines for care of childhood asthma^{6,21} shown in Table 1. The structural indicators concern the prerequisites for providing high-quality care, process indicators refer to interventions designed to achieve good health, and the result indicators focus on improved functional capacity and health-related quality of life.

The proportions of prioritised actions are presented for the total study population and for the following three subgroups: (1) those provided with access to a specialised asthma nurse; (2) those receiving an initial prescription of inhaled corticosteroids in primary care; and (3) those undergoing regular treatment with inhaled steroids. Information concerning regular treatment with inhaled corticosteroids was only extracted from the medical records from 2007 (n=343).

The study was approved by the Medical Ethics Committee at Karolinska Institutet.

Statistical analyses

Statistical values such as proportions and measures of dispersion were computed using standard parametric procedures.

We compared the proportion maintained in medical records within the three subgroups: access to an asthma nurse; initial prescription of inhaled corticosteroids at the PHC; and recommendation of regular treatment with inhaled corticosteroids. The variables in the subgroups were examined from a cluster sample of 18 PHC units. The proportions were calculated and tested in accordance with differences in means for two independent samples adjusted for clustering using the Huber-White sandwich estimator.^{22,23}

Results

All 18 PHCs had a spirometer and a nebuliser for treatment of acute asthma, as well as a pulse oximeter. An asthma nurse and a GP with primary responsibility for asthma care were present at 12 of these centres.

Characteristics of the study population

Of the 424 children included, 85% (n=362) had received diagnoses of asthma (ISD-10 code J45) while the remaining 15% (n=62) were children with a diagnosis of obstructive bronchitis that fulfilled the criteria for asthma. The study population consisted of slightly more boys (54%) than girls; 29% were aged 6 months to 4 years, 23% were 5-8 years of age, 23% were 9-12 years of age, and 26% were aged 13-16 years.

Documentation of areas prioritised in connection with paediatric asthma care according to national guidelines

Patient history

The numbers and proportions of children with documented prioritised aspects are presented for the group as a whole and for the three subgroups in Table 2.

Allergic co-morbidity and a family history of allergic disease were documented more frequently than other aspects in the patient history (67% (n=229) vs. 55% (n=230) of cases). Data on exposure to tobacco smoke were documented in only 14% (n=58) and exposure to furry pets at home in 30% (n=127). The indoor environment was only documented in 5% of cases (n=20). No statistical differences were observed between the subgroups.

Clinical examination

In the total study population, 33% (n=111) had ever performed a

Table 2. Numbers (%) of the medical records for children with asthma that included documentation of various prioritised aspects of the patient history

Prioritised aspects	All children (n=424) Yes	With access to an asthma nurse		p Value	Initial prescription of inhaled corticosteroids at the PHC		p Value	Regular treatment with inhaled corticosteroids		p Value
		Yes (n=291)	No (n=133)		Yes (n=117)	No (n=229)		Yes (n=178)	No (n=143)	
Allergic co-morbidity*	229 (67)	144 (63)	85 (75)	0.223	67 (72)	150 (66)	0.283	120 (67)	97 (68)	0.954
Family history of allergic disease	230 (55)	142 (49)	88 (66)	0.188	61 (52)	157 (55)	0.677	107 (60)	92 (64)	0.485
Exposure to furry pets at home	127 (30)	82 (28)	45 (34)	0.495	39 (33)	80 (28)	0.367	65 (37)	40 (28)	0.116
Exposure to tobacco smoke	58 (14)	44 (15)	14 (11)	0.445	15 (13)	41 (14)	0.714	24 (13)	15 (11)	0.529
Indoor environment**	20 (5)	14 (5)	6 (5)	0.922	5 (4)	14 (5)	0.642	9 (5)	10 (7)	0.211

* (n=343); * Information concerning any of the following: ventilation, dampness, mould odour or condensation on the windows.

peak expiratory flow (PEF) test at some time and a third had undergone such a test during the past 12 months (Table 3). Of the children aged 6 years and older, 22% (n=49) had ever performed a spirometry test and 14% (n=37) had performed such a test during the past 12 months. A significantly higher proportion of the children cared for at PHCs with an asthma nurse had performed a spirometry test ($p=0.003$). Those who had been prescribed inhaled steroids (n=117) at a PHC had undergone spirometry tests (18% vs. 5%; $p=0.032$) and PEF (37% vs. 26%; $p=0.035$) more often than those not receiving treatment with inhaled steroids.

Pharmacological treatment

During the most recent 12-month period, 58% (n=246) of the children had been treated with inhaled steroids, 55% (n=178) of these on a regular basis (Table 4). The GPs at the PHCs involved had initiated and prescribed inhaled corticosteroids in 29% of the children (n=117) and, of these, 41% (n=49) were prescribed regular treatment with inhaled corticosteroids. Treatment with short-acting β_2 -agonists had been initiated at the PHC in 41% (n=166) of

children. Montelukast had been prescribed for only a few of the children. Acute treatment by nebuliser had been administered to 22% (n=88) of the children during the past 12 months, and more frequently (40%) in the youngest age group (0-4 years). Half of those receiving such acute treatment were also given oral corticosteroids.

Non-pharmacological treatment

As shown in Table 5, only 14% (n=59) of the children had ever received patient education regardless of whether or not they had access to an asthma nurse. However, a higher proportion of children treated with inhaled corticosteroids had regularly received patient education compared with those not treated with inhaled corticosteroids (22% vs. 6%; $p=0.006$). Documentation was available about smoking cessation in only one case.

Demonstration of the inhalation technique was documented in 14% (n=58) of the medical records and there was no difference if children had access to an asthma nurse or had been prescribed inhaled steroids at the PHC. Education concerning the use of PEF for

Table 3. Numbers (%) of the medical records for children with asthma that included performance of prioritised aspects of the clinical examination

Prioritised aspects	All children (n=424) Yes	With access to an asthma nurse		p Value	Initial prescription of inhaled corticosteroids at the PHC		p Value	Regular treatment with inhaled corticosteroids		p Value
		Yes (n=291)	No (n=133)		Yes (n=117)	No (n=286)		Yes (n=178)	No (n=143)	
Peak expiratory flow (PEF)* test	117 (28)	83 (29)	34 (29)	0.931	43 (37)	21 (26)	0.035	51 (29)	39 (28)	0.848
Spirometry test* on children aged 6 years or older	37 (14)	35 (12)	2 (2)	0.003	21 (18)	16 (5)	0.032	15 (8)	11 (8)	0.845
Allergy test**	124 (29)	92 (32)	32 (24)	0.345	41 (35)	79 (28)	0.166	68 (38)	32 (22)	0.082

* During the past 12 months (index visits)

** On blood samples employing Phadiatop®, Fx5® or levels of specific IgE and/or skin prick test.

Table 4. Numbers (%) of the medical records for children (N=424) with asthma that included documentation of prioritised pharmacological treatment

Prioritised pharmacological treatment	Yes	No
Inhaled steroids: initiated and prescribed at PHC or on regular treatment	246 (58)	178 (42)
Inhaled steroids initiated by PHC	117 (29)	286 (71)
Treatment with inhaled steroid regularly	178 (55)	143 (45)
Short acting β -agonist initiated by the PHC	166 (41)	237 (59)
Montelukast	10 (2)	392 (98)

PHC=Primary Healthcare Centre.

Table 5. Numbers (%) of the medical records for children with asthma that included documentation of prioritised non-pharmacological treatment

Prioritised non-pharmacological treatment	All children included (n=424) Yes	With access to an asthma nurse			Initial prescription of inhaled corticosteroids at the PHC			Regular treatment with inhaled corticosteroids		
		Yes (n=291)	Yes (n=133)	No p Value	Yes (n=117)	No (n=286)	p Value	Yes (n=178)	No (n=143)	p Value
Patient education*	59 (14)	41 (14)	18 (14)	0.921	23 (20)	33 (12)	0.110	39 (22)	9 (6)	0.006
Smoking cessation	1 (0.3)	0 (0)	1 (1)	0.304	0 (0)	0 (0)	0 (0)	0 (0)		
Demonstration of inhalation techniques	58 (14)	41(14)	17(13)	0.753	23 (20)	33 (12)	0.107	33 (19)	1 (11)	0.145
Education of peak expiratory flow for self-care	30 (7)	26 (9)	4 (3)	0.067	13 (11)	16 (6)	0.048	18(10)	7 (5)	0.176
A planned follow-up:	206 (51)	15 (53)	54 (46)	0.423	75 (64)	129 (45)	0.012	97 (54)	71 (50)	0.366
At the PHC	94 (46)	64 (25)	30 (23)		40 (34)	54 (19)		47 (26)	27 (19)	
At the paediatric outpatient clinic	97 (47)	74 (49)	23 (17)		31 (27)	66 (23)		45 (25)	37 (26)	
At another clinic	15 (7)	12 (4)	3 (2)		4 (3)	11 (4)		5 (3)	9 (6)	

*Patient education includes education concerning the asthma disease, triggering factors and what to do when an exacerbations occurs.
PHC=Primary Healthcare Centre.

self-care at home was documented in 7% (n=30) of cases, more commonly when the children had been prescribed inhaled steroids (11% vs. 6%; p=0.048).

A follow-up was planned for approximately half of the children with asthma, most commonly at PHCs (46%) or at paediatric outpatient clinics (47%). Access to an asthma nurse made no difference in this context. However, children for whom inhaled steroids were prescribed at the PHC were more likely to be followed-up (64% vs. 45%; p=0.012).

Figure 2 summarises the overall percentage of the medical records that documented fulfilment of none, one, two or three to four of the prioritised actions recommended by all guidelines (i.e. performance of spirometry test, demonstration of the inhalation technique, patient education, and data on exposure to tobacco). None of these prioritised actions were performed in 67% (n=286), one was performed in 21% (n=87), two in 8% (n=32) and three to four in only 4% (n=19) of the cases.

Discussion

Main findings

The present study – which, to our knowledge, is the first of its kind – shows that the adherence of healthcare professionals in Sweden to guidelines for care of paediatric asthma is poor and that there is considerable room for improvement. Interestingly, the guidelines concerning pharmacological treatment appear to have been implemented more successfully in primary care than those concerning non-pharmacological treatment such as patient education, demonstration of inhalation technique, and information about the importance of smoking cessation.^{6,24}

Strengths and limitations of this study

One strength of the present investigation is that we employed a relatively strict definition of asthma to ensure that the children included actually have asthma and are therefore candidates to undergo the prioritised actions. Furthermore, the medical records were scrutinised in their entirety to make sure no early interventions were missed.

The fact that most of the participating PHCs were represented

Figure 2. Number of actions documented in the medical records showing scores of 0 to 4 of the following prioritised actions in paediatric asthma care: performance of spirometry test, demonstration of inhalation technique, provision of patient education and data on exposure to tobacco smoke

by a nurse and/or GP initially attending a seminar on asthma might have been indicative of a particular interest in paediatric asthma and therefore better adherence to guidelines. However, this situation did not appear to influence the results obtained.

One weakness was our relatively small study population. At the same time, the medical records were selected randomly from PHCs serving a wide range of neighbourhoods and socio-economic groups. In addition, the children were randomly included and stratified by age groups. Furthermore, we had no information of symptom control measured, for example, using the Asthma Control Test (ACT). However, in routine primary care the ACT test is not commonly used.

We are aware that not all information and actions are accurately documented in medical records, even though the guidelines and Swedish law²⁵ clearly state that all healthcare professionals must provide such documentation to ensure high-quality and safe care.

Interpretation of findings in relation to previously published work

Adhering to guidelines in routine daily practice is a task of great

complexity. Guidelines are often thoroughly written regarding what to do according to the evidence. However, they seldom include guidance on how to alter practice in the context of everyday primary care.

Available guidelines²⁶ indicate that 80% of all children with asthma should require treatment with inhaled steroids or leukotriene antagonists, a proportion greater than the 58% treated in this study. It is also essential to ensure the lowest possible doses are used to achieve symptom control to minimise the risk of adverse effects.²⁷ Of the 58% of children in this study treated with inhaled steroids, only 14% had been given a demonstration of the inhalation technique.

Only 14% of the children had received patient education, which is considered to have an important role in asthma care.⁶ Several studies have demonstrated the importance of patient education and routine follow-up.^{28,29} Moreover, although it is generally recognised that treatment should be based on an agreement between the patient and caregivers,³⁰⁻³² asthma care often fails to incorporate the view of the patient.³³

Furthermore, although the importance of using a proper inhalation technique is highlighted in all guidelines,^{5,6} most of the children in our investigation had never received instructions in the technique. This is in line with a report from the USA where, in most cases, metered-dose inhalers were neither demonstrated nor assessed in connection with paediatric asthma visits.³⁴ Clearly, it is important to ascertain proper use of the inhalation technique at each clinic and with each visit.³⁵

Information concerning exposure to tobacco smoke was present in 14% of the medical records and advice to stop smoking was documented in only one case, even though this action has one of the highest priorities in healthcare.^{5,6} Exposure to tobacco is one of the major causes of deterioration in children with asthma.^{36,37} Children with asthma have a higher risk of hospitalisation if their parents smoke than asthmatic children with non-smoking parents.^{38,39} In addition, a Swedish study recently showed that direct or indirect exposure to tobacco is positively correlated with the incidence of asthma and wheeze in teenagers.⁴⁰ Healthcare providers who care for children with asthma need to be better at raising awareness of the effects of smoking and the importance of reducing childhood exposure to tobacco.^{5,6}

The spirometry test is an important tool in both the diagnosis and monitoring of paediatric asthma and has a high priority in national and international guidelines;^{5,6} furthermore, its use improves asthma control.⁴¹ A study in primary care from Canada showed the importance of using a spirometer as part of the control index for patients from 6 years of age.⁴² In the present study, only a minority of the children older than 6 years of age had ever undergone a spirometry test even though all the PHCs had access to a spirometer.

In the present investigation, access to an asthma nurse was not associated with any substantial improvement in the performance of prioritised actions except that a higher proportion of children with such access had performed a spirometry test. These findings are not consistent with other reports showing that access to an asthma nurse in primary care improves knowledge about and control of the disease, as well as quality of life.^{11,13} In addition, a Dutch study

showed that care provided by a specialised asthma nurse is as effective in the outpatient management of stable childhood asthma as traditional management by a paediatrician or GP.⁴³ Furthermore, attention to clinical guidelines can improve evidence-based nursing practice in connection with the non-pharmacological management necessary for optimal treatment of childhood asthma in which specialised asthma nurses are highly skilled.⁴⁴

Despite the obvious importance of a planned follow-up visit for asthma control as emphasised in national guidelines, only half of the children had a planned follow-up. Such a follow-up should include an assessment of asthma control, comprehensive patient education, demonstration of the inhalation technique, implementation of a self-management plan, and a routine medical examination.^{5,6,45}

Of the children who had received a diagnosis of obstructive bronchitis or cough at the studied PHC, 22% fulfilled the evidence-based criteria of asthma provided by national or international guidelines. Obviously, if the diagnosis is incorrect, treatment may be inappropriate which could result in more unplanned visits due to obstructive symptoms as well as a lower quality of life. On the other hand, diagnosing asthma in children aged 5 years or younger is not easy since respiratory symptoms such as wheeze and cough are generally common in this age group.^{46,47}

Implications for future research, policy and practice

Further studies are needed to understand the complex connection between what to do according to guidelines and how to organise healthcare so that, in practice, support is provided in accordance with guidelines. Adherence to guidelines for primary care of paediatric asthma appears to be poor and should be improved. This situation must be considered when planning education strategies and organising the care of children with asthma.

Conclusions

This review of medical records reveals a clear gap between the actual care provided to children with asthma and national guidelines. For a large proportion of these children, many of the prioritised actions were not performed which might have increased morbidity. Clinical examination and non-pharmacological treatment were the lowest with respect to adherence to guidelines, both with and without access to an asthma nurse.

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Contributorship The authors' contributions were as follows: MJ, IKR(Ingvar Krakau), GH, IK (Inger Kull), MI, AK, ACE planned the present study. IK, AK and ACE supervised the data collection and MJ collected the data. MJ, MI and EH prepared the data for analysis. MJ performed the analysis. MJ, IK, IKR, AK, ACE, MI, EH, GH interpreted the data. MJ drafted the manuscript and MJ, IK, AK, ACE, GH, IKR, MI and EH provided critical review of the manuscript.

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