ORIGINAL RESEARCH

Childhood asthma: reasons for diagnostic delay and facilitation of early diagnosis—a qualitative study

Marianne Stubbe Østergaard*

Department of General Practice, Panum, University of Copenhagen, Blegdamsvej 3, DK 2200 N, Denmark

Received 14 April 2004; accepted 28 June 2004

KEYWORDS

Childhood asthma;
Parents description;
Doctors description;
Clinical history;
Metaphors;
Onomatopoeic;
New asthma concept

Summary

Background: Children with undiagnosed asthmatic symptoms account for much illness and hospitalisation. The aim of the study was to identify reasons for diagnostic delay in childhood asthma and to develop tools for early diagnosis.

Methods: A qualitative study, using semi-structured interviews with the parents of 30 children with asthma aged 2–15 years, combined with 15 GP interviews.

Findings: Asthma symptoms for most of the children started during their first year. The typical symptom pattern reported by parents consisted of insidious recurrent or continuous respiratory symptoms, particularly bad at night, often lasting several weeks or months, provoked or aggravated by common colds or foggy weather. In describing the symptoms, parents focussed on coughing and sputum production. As in other studies, the children's asthmatic diagnosis was obscured by excessive diagnostic emphasis on respiratory infections. The reasons for diagnostic delay seemed to be, typically, that doctors did not pay enough attention to the history of recurrent cough and unspecified respiratory symptoms, just as the parents' use of lay and onomatopoeic terms and metaphors for wheezing seemed to be misinterpreted. Furthermore some doctors relied more on the present symptoms and physical examination, although asthmatic patients may have normal auscultation on examination. Several doctors did not expect asthma in infancy.

Conclusions: The underlying reason for diagnostic delay could be that a former diagnostic definition of asthma, focussing on severe and dramatic cases, was still used by doctors. However, adapting to a new diagnostic concept for asthma, which highlights a history of periodic or chronic cough, wheeze and/or breathing difficulties and the typical asthma pattern in toddlers as shown in this study, may enable earlier diagnosis and treatment.

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Introduction

Children with asthmatic symptoms account for a major proportion of paediatric hospitalisations

* Tel.: +45 35327945.

E-mail address: m.stubbe@gpmc.ku.dk.

[1,2], in which diagnostic delay and insufficient treatment of asthmatic symptoms appear to play an important part [3]. A Norwegian study reported that 75% of the children admitted for acute asthma were below four years of age [4]. The diagnostic delay in childhood asthma results in much disease, family strain, and high health care cost [5].

Diagnostic delay in childhood asthma (usually defined as the interval between the first visit to a doctor with respiratory symptoms and the established asthma diagnosis) of four years was described in 1930 [6] and 1978 [7]. Later, British general practitioners (GPs) reported median delays of 16 respiratory consultations [8] or of three years [9]. Recently in South Africa, three years of diagnostic delay was found in 50% of the asthmatic children studied [10]. Reasons given indicated that GPs trivialised the respiratory queries, overemphasised infectious diagnoses, hesitated to use the diagnostic term 'asthma', and often treated the symptoms with antibiotics [6–8].

Major conceptual changes in asthma have recently been instituted. International Consensus Reports and guidelines [1,11,12] proposed replacing the former definitions of asthma as "reversible air-flow obstruction" or "attacks of wheezing, breathing trouble and expiratory dyspnoea", by pragmatically defining asthma as "chronic or episodic cough, wheeze, and/or respiratory difficulties". Furthermore, looking at the natural history, asthma traditionally has been thought of as a disease starting in school years. However, based on epidemiological studies, more than 50% of asthma cases start before the age of 3 years [13].

Organisationally, Danish children are assigned to a GP and only attend a paediatric department after referral from the GP or after acute hospital admission. This study developed from the author's function as a GP-coordinator between general practice and the local paediatric department with a view to reducing the pressure on paediatric outpatient clinics.

The aim of this study was to identify fundamental reasons for diagnostic delay in childhood asthma and to identify tools for early diagnosis.

Methods

The interviews were conducted in 1996 with parents of 30 children, aged from two to 15 years with a median age of six years, attending an outpatient paediatric clinic with an established asthma diagnosis based on symptoms and response to asthma

therapy. In parallel, fifteen GPs located in Copenhagen were interviewed.

Purposive sampling [14,15] ensured a wide spectrum of asthmatic children in relation to age, asthma severity (ranging from mild to severe), duration of the disease (ranging from one to ten years), as well as social background. It also ensured a spread of GPs in relation to sex, age and type of clinic.

The method was qualitative, based on grounded theory methodology [14], referring to the researcher's aim to develop descriptive analysis or theories embedded in the collected data. The study interviews were semi-structured, with open-ended questions, guided by a theme list. The main themes in the interviews with the parents were a retrospective description of the course of the child's asthma disease and the interaction with the health care system. The themes of the interviews with the GPs focused on their diagnostic process in relation to asthma. The interviews were audio-taped and transcribed verbatim.

The analytical steps were to:

- Assess the internal validity [15] of the parents' interview, comparing core data from the interviews with the paediatric medical records.
- Divide, code, and break the text of the parents' and the GPs' interviews, respectively and separately, into categories and sub-categories, extracting meaning, descriptions, and concepts from the categorised texts, and then correlate the extracted categories with the interview text.
- Make source triangulation, comparing the categories developed from the parents' and doctors' interview text. Most of the extracted categories emerged from both parents' and GPs' interviews.

In the research process, the conceptual changes in asthma became central theoretical analytical approaches for the research question.

Results

The diagnostic delay and use of infectious diagnoses

Prior to the asthma diagnosis, the families experienced numerous sick days and inconclusive visits to the doctor, and the diagnostic delay caused considerable emotional and social strain in the families. Only a few of the parents thought that patients' delay played a role.

Eleven of the thirty children were diagnosed from two to eight years after the respiratory symptoms started. Ten children were acutely hospitalised more than five times for respiratory problems before the asthma diagnosis.

Parents described all kinds of infectious diagnoses given before the asthma diagnosis was established, such as: 'bad colds', resilient colds, viruses, infections, bronchitis, pneumonias, and pseudo-croup implying repeated, but ineffective antibiotic treatment. Some families stopped visiting the GPs because "*they would only give a new antibiotic*". Also, some GPs stated that asthmatic children, initially, were misdiagnosed as infectious airways diseases.

*P2 The first five years he just kept sending us home, 'there was nothing', he said. And when he had fever, then he automatically got antibiotics

P15: The doctor said it was a lung infection. It occurred three times... where he became ill during the night, and I called the doctor. They said he had pneumonia. The third time I thought, this simply cannot be true, because I could see he was not ill the day after and he had no fever

*P = Parent, GP = General Practitioner

Reasons for diagnostic delay

A specific pattern of vague respiratory symptoms
The asthma symptoms, for most children, started during their first year of life. Some children appeared "*to be born with*" asthmatic symptoms.

The typical asthma symptom pattern reported by the parents was recurrent or continuous respiratory symptoms, often insidious rather than acute and dramatic. The symptoms frequently were initiated or aggravated by a common cold or by foggy weather, predominantly in autumn and winter. The condition lasted several weeks or months, often with only shorter intervals of well-being. Symptoms were worst at night.

First and foremost, the parents spoke of protracted coughing, with sputum in the airways and rattling. The coughing was especially at night, causing hours of sleeplessness, and induced by laughing and exercise like climbing stairs. Sometimes the child vomited sputum or seemed to be suffocating during intense bouts of coughing. By some, the sputum was described as "*viscous sputum in the*

lungs". Some children had common colds all the time in infancy.

Many parents described a noisy or heavy respiration (see below). Some parents stressed that the child could not breathe or gasped for air.

Several parents described mood and behavioural changes related to the asthma symptoms such as: The child became tired, worn out, silent, irritated, hysterical, cried always, could not play and lost appetite.

Once diagnosed, the parents noticed rapid improvement with inhalation steroids. An immigrant father stated happily: "*She changed into a new child, once she received the asthma medicine*".

P8 As soon as she caught a common cold...she started to rattle

P16: From when he was very little, he was very restless and coughed always very much...and he almost suffocated by all this sputum he coughed up

P23: The doctor asked for bad periods of breathing trouble. No, she never had that. She just only had this sputum and rattling and when she was sleeping, she was coughing all the time

P15: And I could feel a pattern...when he got irritable and obstinate, then it was almost always certain that his peakflow was low

Onomatopoeic and metaphors for wheezing

In describing the symptoms the parents seldom mentioned the medical term 'wheeze'. Instead they tended to use lay expressions and onomatopoeic terms like *rattling*, *squeaking*, *whistling*, *snorting* or "*it simply boiled when she breathes*" for the asthma sounds, or expressions like "*they could hear it on the respiration*", "*she gasped and the breath was heavy*". Also metaphors were used such as: "*She sounds like a decalcified coffee machine*" or "*she sounds like a bellows*" or like "*one who had been to the pub*" or "*he is snoring like a bull*".

P6: The doctors asked: Does he wheeze or rattle? Well, you know all these words. I think it can be difficult to distinguish. Because he never wheezes. But you can hear, that when he eats, he breathes like a bull...so nothing resembling wheezing or rattling or anything like that...he snorts

Doctors focussed on the momentary impression and auscultation, not on the long history

Some parents stated that the doctors did not listen carefully to the history of the child's long and up-setting respiratory symptoms, but seemed to focus on present symptoms and seemed to rely on their momentary impression in the consultation. Primarily, children were affected during sleep. However, sitting in the consultation, or arriving at the hospital, the child was often in better condition. Therefore, the momentary impression of the child gave the doctor an undramatic picture.

Also, doctors seemed to put a lot of value on auscultation. Absence of specific stethoscope sounds (ronchi) was interpreted by some doctors as not being asthma, even though the child had typical asthmatic symptoms.

Several doctors stated that the asthma diagnosis in infants is difficult because of vague diagnostic criteria and difficulties in discerning between common coughs, upper respiratory tract infections and asthma. In cases of classic attacks with wheezing and breathing trouble in the consultation, the asthma diagnosis was obvious and easy. Some doctors would diagnose asthma only in these cases.

P29: The doctor said: 'But it is not asthma, I have examined the child thoroughly and there is nothing to be heard on the lungs'

GP1: It is a very difficult diagnosis. What remedies do I have? I have my experience and a story, a course... If you take a child of 7–8 months. The parents usually come because of the child's cough... There is incredibly much coughing... Suddenly one realises that the many common colds could be something asthmatic

GP8: Asthma is an easy clinical diagnose, because you can hear it. Patients come and say: I have asthma, then you listen (auscultate) and say: 'But, you really don't have asthma, because there is nothing to hear'... I certainly do not have any asthmatics, neither children nor adults, without the typical sibilant ronchi

The first few years it was called 'wheezy bronchitis'

Families said that, when the child reached the age of about 4 years, the same symptoms which earlier had been called wheezy bronchitis, were sud-

denly and surprisingly classified as asthma. The distinction between asthma and wheezy bronchitis seemed to be confusing, for the parents as well as for some GPs. Some doctors doubted the presence of asthma in infancy.

Some GPs were reticent to give the asthma diagnosis to children, partly because they did not expect asthma in toddlers, felt uncertain about the diagnosis and partly not to stigmatise the child. The doctors' sense of stigmatising the child seemed to come from their classification of asthma as a serious lifelong disease.

GP8: Among children under the age of four or five, I do not remember that I ever have had any real asthmatics, but I might be wrong. I think, in relation to age, children younger than three or four years of age have wheezy bronchitis. However, I could be wrong. In fact, we have children with asthma, and perhaps it was real asthma when they were small

Discussion

This study was qualitative, based on interviews with parents of 30 asthmatic children, and with 15 GPs in Copenhagen. In spite of a purposeful sample relating the severity of childhood asthma, the sample may represent children with stronger asthma or with longer diagnostic delay than the background asthmatic population, as the children all attended an outpatient clinic. The internal validity [15] was high, comparing the parental interviews with previously reported work. Generally, the extracted sub-categories from the interviews with parents and doctors matched and clarified each other.

Most children in this study developed respiratory symptoms in infancy. As in other studies, the children's asthmatic conditions were obscured by excessive diagnostic emphasis on respiratory infections [5–7] and the term 'wheezy bronchitis' [3,7,8]. The diagnosis of wheezy bronchitis signalled a minor condition, not needing much explanation or treatment.

The typical asthma pattern reported by the parents was insidious, recurring or continuous respiratory symptoms, particularly bad at night, provoked or aggravated by common colds or foggy weather, often lasting several weeks or months, and often induced by laughing and exercise. In describing the symptoms, parents focussed on coughing, rattles, sputum and noisy respiration along with change of

mood and behaviour. The terminology of wheezing was seldom mentioned. Instead, parents seemed to use lay expressions, metaphors and onomatopoeic terms. Other studies have also found major conceptual differences between patients' and doctors' use of the term 'wheeze' [17–19], even though reported wheeze is the cornerstone of asthma diagnosis. Sputum in the airways seemed to be prevalent in the children, although it is not considered a core symptom in asthma.

Several doctors stated that the diagnosis of asthma in infants is difficult because of vague diagnostic criteria. The study indicated that some doctors in their diagnostic process focussed on readily observable symptoms and signs and were not attuned to trace the pattern of the child's often long medical history [16]. Stethoscopic wheeze, linked to the earlier definition of asthma, was for some doctors an essential (pathognomonic) feature of their diagnosis of asthma. However, stethoscopic wheeze, although highly specific for asthma, is not a reliable indicator of childhood asthma because of a low sensitivity [20], and asthmatics may have normal auscultation in spite of significant airflow limitation [12].

Applying the theoretical framework outlined in the introduction, the diagnostic delay may be caused by some doctors' use of an earlier, narrow diagnostic definition of asthma, which emphasized dramatic, severe exacerbations with the presence of observable signs - the tip of the iceberg. However, the medical histories conveyed by the parents in this study were much more in line with a new diagnostic concept of asthma based on long-term symptom pattern [1,11].

Perspectives: Early diagnosis and treatment

Early treatment in mild asthma reduces the illness of the child as well as severe exacerbations and admissions [21–25]. Studies throughout the last decade indicate benefits from inhaled corticosteroids (ICS) in infants and children after recurrent periods of asthma symptoms [3,22–24], either given intermittently if symptoms are episodic [23,24] or when given for longer periods if there are persistent asthma symptoms [21,22]. In partnership with the patient, GPs are advised to determine the lowest effective dose of ICS to control the symptoms [12], including shorter or longer breaks, and revert to higher doses of ICS treatment at the first signs of asthma exacerbations [24].

Combining the newer approach to asthma definition [1,11] with the presence of an extended med-

ical history in line with the parents' description in this study, and the knowledge that asthma often starts in infancy [13], should reduce diagnostic delay and facilitate early relevant treatment.

When informing parents of a possible asthma diagnosis, it is important to emphasize that the new concept of asthma includes a mild and transient asthmatic condition.

Diagnosis of asthma in infants is particularly difficult, since it is based on vague demarcations. A pragmatic diagnostic time frame has been proposed to raise the suspicion of asthma: a minimum of three periods of at least two weeks of asthmatic symptoms [25]. The risk of over-diagnosis of asthma in children with persistent cough exists [26], as cough is a frequent and unspecific symptom in toddlers. In addition, the cornerstone symptom of wheeze seems to be poorly interpreted and seldom used by parents.

Given the subtle nature of respiratory symptoms, future research may need to examine the validity of a combination of one or more parental expressions and sub-categories of asthma symptoms, extracted from qualitative studies.

Further clarification of the demarcation between asthma and simple repetitive respiratory infections is still a challenge.

Acknowledgements

The study has been approved by the Danish Scientific Ethical Committee.

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