Improving care in paediatric asthma

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Chapter 12: Children with asthma: do we answer their questions?

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Submitted.
Abstract

Background
Much is known about the care and treatment for children with asthma. However, this is all adult-driven. We wanted to know which problems, concerns and thoughts children with asthma themselves have.

Methods
The children were asked which questions they wanted to ask the pediatrician. These questions, worries and concerns were collected during asthma nurse led educational sessions for children with asthma.

Results
The questions of this group of children, representative of the patients we care for, dealt with epidemiological matters, daily life and the efficacy of the treatment, fears and questions about the future, as well as personal questions for the pediatrician.

Conclusions
Children with asthma have significant questions, fears, worries and concerns. Discussing these issues with them is important.
**Introduction**

Asthma is a common, chronic disorder, influencing the daily life of children with asthma. International guidelines have been developed to achieve and maintain adequate control of the disease.\cite{1,2,3} The impact of the disease can be measured by standardized questionnaires which enable us to measure quality of life and functional health status of these patients.\cite{4,5}

One of the important components of childhood asthma care is to develop a partnership with the child and their care givers. In order to achieve this, educational sessions can play a major role. The education of children with asthma and their care givers comprises issues such as the mechanism of disease, inhaled medication, the correct use of inhalers, avoidance of allergens and non-specific triggers, and self-management.

However, these instruments are all adult-driven. We feel that it may be equally important to know what concerns are actually experienced by these children themselves. Addressing these issues may increase adherence to treatment and their quality of life.

We offer these children a comprehensive educational course. During 7 sessions a pediatric asthma nurse discusses the items mentioned above. Furthermore, they also learn to cope with reactions and behavior of peers and adults. During the course, the children are encouraged to formulate questions they would like to ask the pediatrician. We collected these questions and evaluated if their questions would have been answered if we address the educational issues mentioned in international guidelines.

**Methods**

At our outpatient asthma clinic in a large teaching hospital in the northern part of the Netherlands, children 8 through 12 years of age, diagnosed with asthma according to international guidelines,\cite{2} are encouraged to participate in a comprehensive 7 session course. The course is entitled: ‘Asthma, at home, and at school’, and has been developed by the Dutch Asthma Foundation.\cite{6} During the course the children are encouraged to formulate questions they would like to ask a pediatrician. At one session, pediatricians (TV and AK) are invited to answer these. Subsequently, we evaluated whether their questions would have been answered if we address the educational issues mentioned in international guidelines. Patient characteristics were collected from their medical records.

The aim of this paper is to describe the questions children with asthma have. Therefore, statistical procedures were not performed, and approval of the medical ethical committee was not sought.
Results

Seventeen children participated in the 2 most recent courses. Patient characteristics are presented in table 1. The mean age was 10 years (range 8 – 13 yrs), 9 of them were boys. The mean duration of asthma was 5 years (range 1 – 10 yrs), and 16 (94%) of them used inhaled corticosteroids (ICS), with a mean daily dose of 346 µg (median 200 µg/day, range 200 – 1000 µg/day). Nine (53%) children also used long acting β2-agonists. We are not informed about the number of asthma attacks in the preceding years, but we know that none of these children were admitted to the hospital because of an asthma attack in the preceding 4 years.

The questions were collected and categorized in four groups (table 2); only questions asked more than once are discussed in this report.

The first questions are about the cause and epidemiology: ‘why do I have asthma, whilst my brother and sister do not?’ and ‘how many children have asthma?’.

The second group of questions was about daily life and treatment: ‘why do I have shortness of breath when I am angry or sad?’, ‘does the medication still work if I use it for a long time?’, ‘can I stop taking medications when I am doing well?’, and ‘do children with asthma have to take an influenza vaccination?’.

Questions concerning the future and their fears were: ‘will I recover from asthma?’, ‘can one die of asthma?’, and ‘will my children have asthma too?’.

Finally, the children had a personal question for the doctor: ‘do you yourself have asthma?’.

None of their questions would have been answered by addressing the standard educational items.

### Table 1: characteristics of the 17 participants of the courses.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (range) (years)</td>
<td>10 (8 – 13)</td>
</tr>
<tr>
<td>Sex (male/female)</td>
<td>9/8</td>
</tr>
<tr>
<td>Mean duration of asthma (range) (years)</td>
<td>5 (1 – 10)</td>
</tr>
<tr>
<td>Allergic asthma</td>
<td>14/17</td>
</tr>
<tr>
<td>Maintenance inhaled corticosteroids</td>
<td>16/17</td>
</tr>
<tr>
<td>Mean daily dose of inhaled corticosteroids* (range) (microgram)</td>
<td>346 (200 – 1000)</td>
</tr>
<tr>
<td>Long acting β2-agonists (number)</td>
<td>9/17</td>
</tr>
</tbody>
</table>

* 14 of the 16 children were on fluticasone diproprionate.
Discussion

In this article we report fears, worries and fantasies of a group of children with asthma who we see in our outpatient clinic and evaluated whether questions of these children would have been answered by addressing the educational issues mentioned in international guidelines. To the best of our knowledge, a study like this has never been performed before, although a study about the fears and concerns of parents have been published.7

We will reflect on the questions formulated by the children who attended the course. Many of these children wanted to know how many children have asthma. More specifically, they wanted to know how many children also have this chronic condition affecting daily life whilst playing outside and playing sports, affecting family life because they have to take medication, visit a doctor regularly, and the family may not be able to go places due to avoidance of triggers, and affecting their position in the family because of allergies, the family pet can no longer stay in the house. The knowledge that about 10% of children have asthma,8 can make them aware of the fact that there is a high probability that children in their neighborhood and/or school class have asthma too. Knowing this may make them feel less “special”, as every child wants to be as normal as other children. We feel that health care professionals caring for children with asthma should ask the child how their life is affected by asthma. This way, an individual child will have the opportunity to have his or her questions answered.

All of the children used preventive asthma medication such as inhaled corticosteroids (ICS). As professionals, we constantly emphasize the need to inhale the medication correctly and every day to avoid symptoms. By doing so, we put pressure on the child. It is therefore not surprising that they want to

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Table 2. Questions formulated most frequently by children with asthma.

<table>
<thead>
<tr>
<th>Category</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epidemiology</td>
<td>Why do I have asthma, whilst my brother and sister not?</td>
</tr>
<tr>
<td></td>
<td>How many children have asthma?</td>
</tr>
<tr>
<td>Daily life &amp; treatment</td>
<td>Why do I have shortness of breath when I am angry or sad?</td>
</tr>
<tr>
<td></td>
<td>Does the medication still work if I use it for a long time?</td>
</tr>
<tr>
<td></td>
<td>Can I stop taking medications when I am doing well?</td>
</tr>
<tr>
<td></td>
<td>Does every child with asthma have to take an influenza vaccination?</td>
</tr>
<tr>
<td>Fears &amp; future</td>
<td>Will I recover from asthma?</td>
</tr>
<tr>
<td></td>
<td>Can I die of asthma?</td>
</tr>
<tr>
<td></td>
<td>Will my children have asthma too?</td>
</tr>
<tr>
<td>Personal</td>
<td>Do you yourself have asthma?</td>
</tr>
</tbody>
</table>
know if there is a possibility of stopping medication. Their fear that the medication does not work after a long time is very recognizable and has been the subject of formal studies.9,10 That asthma affects daily life is demonstrated by the question about having shortness of breath in periods of anger and sadness. This demonstrates that symptoms can arise unpredictably and this unpredictability is of concern to the child.

Vaccination causes pain and distress and it is not surprising that children want to be sure about its necessity. A recent Dutch study in which the influence of influenza vaccination was studied in a double blind controlled trial demonstrated that vaccination is of limited value and therefore should be reconsidered.11 Based on the findings in this study, we no longer advise influenza vaccination in all children with asthma.

The question about the possibility of dying of asthma impressed us immensely. Especially since none of these children had been admitted to the hospital because of asthma, they may have had frightening periods of shortness of breath, and know what it feels like to fight for air. Although the number of children dying of asthma has fallen dramatically,8 apparently some of the children attending the asthma courses were afraid that they may die of asthma. Therefore it seems to be sound to discuss this item and to reassure them.

It was striking that even at this young age children were concerned about the possibility that their offspring will have asthma too. This might not only be a theoretical question for them; they know what it is to have asthma and how asthma may affect their life. Moreover, some of them might have parents or siblings suffering from asthma. Although at this point we know that genes are one of the factors involved in the development of asthma,12 more insight into this is not only of scientific interest. With a better understanding of the causes of asthma, we may be able to give a more explicit answer to the children.

We were somewhat puzzled by the question if we have asthma ourselves. The children said that they would like to know this, because they wanted to know if we recognize the feeling of shortness of breath and fears, they have during an asthma attack. Even if we do not have asthma ourselves, we may need to address that we can imagine that it can be frightening to experience an asthma attack. Additionally, we have to give them the opportunity to express their fears and fantasies about the asthma attacks they have.

The scope of the questions is so wide that it is not surprising that these questions are not part of formal educational material.
In conclusion, with this study we realized that it is important to ask children with asthma in an open manner about their thoughts, fears and worries and how the disease affects their lives. Educational programs do not necessarily answer all questions these children have. Questions of children with asthma may be left unanswered if we do not explicitly give them the opportunity to ask these questions. Therefore, health care professionals caring for children with asthma, should give them the opportunity to talk about their fears and worries. This way, unnecessary fears and worries can be taken away. It is not unlikely that this will result in a better adherence to treatment and a better quality of life.

We thank our colleague dr. J.Collins for reviewing the English. We thank the children, participating in the course, for their open minds and open hearts.
References.
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