

REGULAR ARTICLE

Parental illness perceptions and medication perceptions in childhood asthma, a focus group study

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ABSTRACT**Aim:** Asthma treatment according to guidelines fails frequently, through patients' nonadherence to doctors' advice. This study aimed to explore how differences in asthma care influence parents' perceptions to inhaled corticosteroids (ICS).**Methods:** We conducted six semistructured focus groups, including 44 parents of asthmatic children (2–12 years of age, treated in primary or specialist care). Verbatim transcripts were analysed with standard qualitative research methods.**Results:** Parents decided deliberately whether ongoing ICS use was useful for their child. This decision was based on their perceptions about illness and medication. In primary care, this issue was hardly ever discussed with the health care provider because regular scheduled follow-up was unusual. In specialist care, regular scheduled follow-up was usual, and parental perceptions about illness and medication were discussed and modified when needed. Parent-reported adherence was lower in primary care than in specialist care.**Conclusion:** This focus group study illustrates how strongly parental perceptions of illness and medication influence adherence to health care providers' advice and that such perceptions can be modified within a strong doctor–patient partnership, improving adherence.**INTRODUCTION**

Low adherence to inhaled corticosteroid (ICS) treatment in children with asthma is one of the main reasons why asthma is still associated with significant morbidity, and goals set in the GINA guidelines are frequently not met (1–3). Reasons for poor adherence to ICS are not fully understood, but patients' perceptions about illness and medication appear to be at least as important as external, nonmodifiable factors such as socio-economic status and race (4–8). Because most health care providers do not discuss patients' perceptions of their illness and its medical management during the consultation, they are frequently unaware of differences between the parents' perception and the professional model of the disease (9). This makes it impossible to focus on such differences. Building a partnership with patients (and their parents), as suggested by the most recent revision of the guidelines, may improve awareness of different perspectives between patients and physicians (10). However, the way such partnership is reached is different between primary

care and specialist care caused by differences in organization. Most asthma care takes place in primary care, where patients and physicians tend to have a long-standing relationship. Most primary care physicians provide asthma care without specific support from specialized asthma nurses, and planned follow-up visits are uncommon – the decision to visit the doctor is primarily made by the parents (11). According to their guidelines, primary care physicians refer patients to specialist care when asthma control is not achieved by low-dose ICS maintenance treatment. In our paediatric specialist clinic, asthma care is delivered by paediatric chest physicians together with asthma nurses, and all newly referred patients receive comprehensive and tailored asthma education (12). We schedule frequent follow-up visits until guideline goals for treatment are met.

This study aimed to explore how these differences in asthma care influence parents' perceptions about asthma, its treatment and how they qualify the relationship with their health care providers. A qualitative approach was chosen because this allows a rich interpretation of patients' perspectives, experiences and roles (13). By organizing focus groups, we aimed to reach dynamic conversations where the interaction between parents would provide supplemental information.

Abbreviations

ICS, inhaled corticosteroids; GINA, Global Initiative for Asthma.

METHODS

We performed a focus group study according to published guidelines (14).

Six focus groups of parents of children with asthma were convened: three from the paediatric asthma clinic at our hospital and three from five primary care practices in the catchment area of our hospital. These practices represented city and rural area, and small and large practices. The family physicians involved had contributed to previous research of our paediatric asthma clinic, they had expressed an interest in childhood asthma care and were supportive of regional guidelines for the management of asthma. Parents of children aged 2–12 years with a doctor's diagnosis of mild to moderate persistent asthma who had received at least one prescription for ICS in the last year were eligible for inclusion in the study. From an alphabetic list, consecutive parents were approached, and after giving informed consent, they were included until groups were full (eight parents). No preset characteristics of parents or children were used for inclusion, because characteristics that determine parental perceptions are unknown.

Each focus group interview, which lasted approximately 2 h, followed a semistructured interview guide of 10 open-ended questions (see Data S1), asking parents about their perceptions of asthma and its treatment, and on the organization of care. The interviews were led by a professional journalist without specific medical knowledge, who encouraged parents to express their views freely and who clarified views and expressions where needed. One of the authors (TK) attended the sessions, took field notes and debriefed the moderator after each interview to record her impressions of emerging themes. This information was used to structure the subsequent focus group interviews. After reviewing the transcripts of six focus groups, it was concluded that saturation had been reached (14).

Each focus group was audio-taped and transcribed verbatim prior to data analysis.

Before conducting the focus groups, a codebook was put together, including items from the beliefs about Medicines Questionnaire (15). New codes were added for emerging themes from field notes, debriefing and during the coding process itself, to allow capturing all relevant data. The transcript of the first focus group interview was coded independently by two researchers (TK, HR). Cohen's Kappa was 0.78 (where 0 = no agreement and 1 = perfect agreement), indicating good agreement for classification by code. Subsequent transcripts were coded by one of the researchers (HR) and cross-checked by another (TK). Differences in coding were resolved by consensus. Codes were grouped into three themes: parental perceptions about illness and medication, self-management including self-reported adherence and issues relating to asthma care and health care providers. A provisional theoretical model explaining the results was developed by two researchers and modified and extended in discussions between all authors.

The Medical Ethics Review Board of our hospital judged that this study, because it involved only adult volunteers, did not require formal ethical approval under Dutch law.

RESULTS

From the primary care practices, parents of 38 children were invited to participate. Parents of 20 children consented, and 24 parents, representing 18 children, attended. From the paediatric asthma clinic, parents of 42 children were invited to participate, parents of 17 children accepted and 20 parents representing 16 children participated. All parents had full health insurance (which is mandatory in the Netherlands), most were Caucasian (which comprises >90% of patients in the catchment area of our hospital) and most were from (upper) middle class backgrounds. The mean age of the children of the parents in the focus groups was 5.7 years, ranging from 2 to 12 years. Fourteen children were under the age of five and had primarily viral-induced wheeze exacerbations. Most preschool viral-induced wheeze patients from secondary care were hospitalized for an exacerbation, whilst none of the patients from primary care had ever been referred or admitted to hospital. All children 5 years of age or older had mild to moderate persistent asthma; the large majority were atopic.

The principal findings of the focus group interviews are presented separately for primary care and specialist care. These findings are illustrated by quotes about common perceptions of illness and medication and about health care providers (Table 1).

Primary care

Parents reported that after the initial visits to the health care provider, during which a diagnosis was made and maintenance medication was prescribed, they did not receive regular follow-up appointments. Parents would receive repeated inhaled corticosteroid prescriptions for their child without seeing a health care provider for up to three years, with parents managing their child's asthma on their own. Parents would only visit the health care provider when they could not manage their child's asthma problems by themselves anymore. Parents considered this method of self-management without consulting a health care provider as entirely logical. They were comfortable with it, because they viewed themselves as being responsible for making decisions on issues such as medication use. These decisions were based on their perceptions about illness and medication (Table 1). Consequently, they used the prescribed medication depending on how they valued their child's need for medication and on their concerns regarding medication use. If parents were convinced of the necessity of using ICS, this was mostly because they had observed an improvement of their child's symptoms after starting ICS, or it was based on an experience in the family that patients with asthma benefit from ICS. Although some of these parents would give ICS on a daily basis to their child, most would use ICS only intermittently or stop it altogether, arguing that their child's asthma was not severe enough to justify daily use of medication. Most of these parents expressed resistance against medicines in general; the feeling that children should use as few medications as possible was common.

Persistent asthma symptoms in the children were described frequently. Parents regarded these symptoms as

Table 1 Parental quotes from the interviews illustrating the key findings**Similarities in primary care group and secondary care group***Views on the partnership with the health care provider for taking decisions on treatment*

'The paediatrician suggested to lower the dose, but I said; he is now doing well, let's keep the dosage at two times a day'.

'When my son has an asthma attack, I know he will receive oral prednisone when we visit the doctor. But I prefer he recovers without. Therefore, together with my husband we decide when the problems with breathing are severe enough to visit the doctor for receiving a prescription for oral prednisone'.

'I think the time changed that doctor's are the 'all-knowing'. Therefore, nowadays it is more a two-way conversation. Again, it is your child, you know the best if he is ill'.

'In general, we don't have to debate very much, the doctor takes usual the decision we had in thought'.

'When I say I want to stop de medicines, the asthma nurse does not automatically reject my idea. Her reaction is that the complaints of my child can return in a very severe way, so she keeps mentioning the importance of the medicines. But she does not say I can't do that. This in contrary with the general practitioner'.

Perceptions about resistance to medicines in general

'It is poison'./'It is trash'./'Medicines are bad'.

'I don't like medicines altogether'.

'That doctor said that there are no side effects when using this medicine for a long period of time, but in the past they were saying that about a lot of medicines, and they turned out to be wrong'.

Differences between primary care group and secondary care group*Perceptions about asthma and the treatment with ICS in the primary care group*

'Most illnesses in children disappear by themselves'

'If you continue preventive medicine you can never find out whether the child can do without'

'I compare it with a sprained ankle: maybe you need crutches first, but for full recovery you have to walk without them'

'We wanted to find out how he would do without his medicine. Well, he was fine. So now we only give the medicine when he needs it'

'I don't want to burden my child with medicine of which I am not sure it will help. With salbutamol, it is clear, but with fluticasone, you just have to assume that it works. And that is really difficult'

'It doesn't work as well when you use it on a daily basis'

Perceptions about asthma and the treatment in the secondary care group

'Her asthma may not disappear, but with the medicines you can suppress it'

'The well-being of my daughter depends on the use of the medication'

'First I thought that periods with no symptoms means she had control over the asthma by herself and medicines were no longer needed. Now I have learned this is the wrong assumption'

'The fluticasone is a preventive medicine, I try to say, just take your meds, you can reach the age of one hundred years using them'

'If you are thinking about the kind of medicines you put into your child, sometimes it upsets you, but asthma upsets you more. So, you have to give the medicines'

'He uses it on a daily basis, it prevents complaints'

belonging to having asthma and not as a reason to visit the health care provider or to step up medical treatment. Parents described the asthma care and the amount of information received as minimal, but adequate, and they were satisfied with their primary care practitioner.

Specialist care

Parents reported that in specialist care, all children received regular follow-up by the paediatric chest physician and by the asthma nurse, with a frequency of at least two visits a year. All parents were convinced of the necessity of ICS, preventing their children from having symptoms. This belief was consistent between parents, although concerns about the use of medication in general were common. These parents expressed the opinion that their child's need of being treated with ICS outweighed their concerns regarding the risks of daily use of ICS. Although all parents reported to be adherent to the advice of daily use of ICS, those with strong concerns about medication were eager to diminish the dose. As follow-up was regular, they felt free to discuss this topic with the health care provider, and in their opinion changing the medication dosage was a shared decision between parents and the medical team. Parents were very satisfied with the asthma care. They particularly valued the fact that they were taken seriously and that they were acknowledged as the people knowing their child best. The asthma nurses were highly valued as being easily approachable, well-

trained and because they provided lots of practical advice. Parents felt free to discuss issues such as their concerns about medicines or the use of alternative and complementary treatment with these nurses. Many parents expressed strong criticism about the health care providers in primary care. They did not feel having been taken seriously by these health care providers in their concerns about their children. Consequently, their view on their child's symptoms and treatment differed from that of the health care providers, and this prompted parents to ask for referral to specialist care. Parents emphasized that they had to be very assertive to receive the treatment that they felt their child needed. Another complaint about primary care was the limited amount of information patients received, making it difficult to self-manage their child's asthma.

Feedback of study findings to participating physicians

The results of our focus group studies were discussed with the family physicians and paediatric chest physicians in a group meeting. All participating physicians confirmed that the parents' reports of asthma care were a representative description of current asthma care in their practices.

DISCUSSION

This focus group study with parents of children with asthma provides important clues to understanding how differences

in asthma care facilitate or hamper adherence to ICS treatment in children with asthma. Two main results emerged from the inductive analysis of the focus group interviews.

First, parents play a pivotal role in the management of their child's asthma. Health care providers can not force asthma treatment upon these children; parents decide whether they will follow medical advice for their child's condition. This parental decision is based on their own perceptions about illness and medication. Even a satisfying long-term relationship with the primary care physician does not prevent parents from critically approaching prescriptions for maintenance medication for their child. This is in accordance with previous qualitative studies' findings showing how parents take the medical care of their child's asthma into their own hands by balancing the perceived need for ICS against their concerns about (side effects of) medication (4,16–18). This finding emphasizes the importance of parental perceptions about illness and medication and illustrates how strongly such perceptions influence parental behaviour regarding health care providers' advice (4–6,8).

Second, the results of this study strongly suggest that these powerful parental perceptions about illness and medication can be modified by health care providers during close and intensive follow-up. In contrast to parents in primary care, most parents in specialist care adopted the professional model of asthma (Table 1). The regularly scheduled follow-up in specialist care and the involvement of asthma nurses offer the opportunity to listen carefully to parents, to explore and understand their views on illness and their attitudes towards asthma medication, which is needed to develop a true patient/parent–doctor partnership. Being aware of the family's needs and perceptions, tailored information can be given (19). Our results support the hypothesis that such close follow-up allows modification of these parental perceptions about illness and medication (20). This underscores the importance of building a partnership with parents, characterized by listening to their views and perspectives on illness and medication and by shared decision-making. Modifying parental illness and medication perceptions during long-term close follow-up allows better self-management and improved adherence to health care providers' advice. This helps to understand how quality improvement strategies for childhood asthma care, including communication education of physicians or group discussions with parents based on the concept of concordance, improve asthma outcome (21,22).

Although our findings strongly suggest that the observed differences in parental perceptions about illness and medication between primary care and specialist care were caused by the different organization of care, other explanations must be considered. It could be argued that a higher degree of asthma severity or poorer asthma control in patients from specialist care increased the parental sense of usefulness of maintenance medication for their child. Although we did not formally assess asthma severity and control level in the children with asthma whose parents we interviewed, the overall impression from the focus groups

was that the degree of asthma severity was similar between children from primary and specialist care, the only difference being a larger history of hospitalizations in the secondary care group children. Although this may have affected parental perceptions on usefulness of medication in the preschool children concerned, it can not explain the large differences in parental perceptions between the whole secondary care group when compared to the primary care group. Furthermore, children in primary care appeared to have poorer asthma control with frequent asthma symptoms, and this did not affect the parents' view on the usefulness of maintenance medication. Previous studies from the USA and from the Netherlands have also shown little difference in childhood asthma severity between primary and specialist care (11,23).

Focus group methodology was chosen because this is superior to quantitative surveys in exploring parents' perspectives and beliefs on the management of asthma (13). However, the time- and labour-intensive nature of qualitative research imposes the limitation that it can only be conducted with small samples. As a result, findings are not immediately generalizable to the larger population, in particular because most parents were Caucasian middle class with good access to health care and full health insurance. However, in a study among low-income urban families, caregiver and child perceptions about illness and medication were also found to be a major barrier to asthma care (8). Other studies showed that such perceptions hamper adherence more in low-income, minority populations (4,7). Although it might be tempting to think that such misperceptions about illness and medication are the result of ignorance and would be more common in lower socioeconomic strata, our results, remarkably, show that such counterproductive parental perceptions about illness and medication are an important barrier to adherence to maintenance treatment, even in a group of affluent and well-educated parents. This stresses the importance of a strong doctor–parent partnership where such perceptions can be discussed and modified.

A final limitation is that we had no objective data on adherence in our study group, which could corroborate the parental reports of adherence. Given the cross-sectional nature of our study, monitoring adherence with electronic logging devices or by weighing canisters was not possible. It has been shown that checking pharmacy dispensing data on inhaled corticosteroids in children is as unreliable as parental reporting of adherence (24). Therefore, it is unlikely that we could have improved the accuracy of our assessment of adherence in the context of this study. Although it is likely that parental reporting of adherence is an overestimate of true adherence, it is unlikely that this overestimation differed between the groups of parents that we studied.

In summary, this study shows the pivotal role parents have in the management of childhood asthma. Parental decisions about the treatment of their children are highly influenced by their perceptions about illness and medication. This study suggests that health care providers can modify such perceptions by offering regular follow-up in

which consultations are characterized by collaboration between health care providers and parents. This approach may help to improve adherence and increase asthma control.

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CONFLICTS OF INTEREST

The authors have no conflict of interest related to this article.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

Data S1 Semistructured interview guide.

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