

ADOLESCENT ASTHMA

Experiences of living with asthma – a focus group study with adolescents and parents of children with asthmaM. Jonsson, RN^{1,2}, A-C. Egmar, RN, PhD^{3,4}, E. Hallner, RA^{1,5}, and I. Kull, RN, PhD^{5,6,7}

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Abstract

Objective: The goal for asthma treatment is that every individual, so far as possible, shall live without symptoms and exacerbations. Patients and health care professionals sometimes have different perceptions of what is important for achieving good quality of life. This work aims to describe the experiences among adolescents as well as those of parents with young children living with asthma. **Methods:** Four focus group interviews were performed, two with parents of young children and two with adolescents. The data were qualitatively analyzed, using Systematic Text Condensation. **Result:** Three themes relevant to the participants' experiences of living with asthma were presented; *strategies, frustrations and expectations*. The adolescents wanted to be like their peers and developed their own *strategies* for self-management of asthma, which included not always taking medication as prescribed. The parents emphasized *frustration* regarding not being believed, lack of understanding feelings of loneliness, or anxiety. One identified expectation was that the participants wanted to be met with competence and understanding in asthma care from health care professionals. Another expectation expressed among parents was that teachers in nursery and primary schools should have more knowledge and understanding on how to care for children with asthma. **Conclusion:** Living with asthma leads to developing personal strategies in self-management of asthma. Moreover both parents and adolescents had expectations of being met by competent and understanding health care professionals. Developing a partnership between patients and health care professionals could be a successful way to improve the care of patients with asthma.

Keywords

Asthma care, experiences, health care, interviews, partnership

HistoryReceived 5 July 2013
Revised 2 October 2013
Accepted 3 October 2013
Published online 20 November 2013**Introduction**

Asthma is one of the most common diseases among young children and adolescents and can affect health-related quality of life (HRQoL) to varying degrees [1–3]. The majority of children with asthma are treated within primary care or in a child outpatient clinic. However, primary care professionals' adherence to asthma guidelines has been reported to be poor and could lead to deficiencies in the care of patients with asthma [4–6]. The goal for asthma treatment is that every individual, so far as possible, shall live without symptoms and exacerbations [7,8], but many children fail to achieve this [9]. Uncontrolled asthma can have severe implications for daily life such as missed schooldays and working days for parents as well as impaired HRQoL [8–11]. Sometimes, patients with asthma are unaware of ways their asthma can be controlled

[12]. In addition, the patients' view of living with an asthma diagnosis involves psychological aspects [13], such as fear of exacerbations and the anxiety and tiredness they feel when asthma symptoms affect them. Unfortunately asthma control guidelines fail to take such symptoms into account [8,14]. Pharmacological treatment is an important part of asthma treatment and many patients with asthma have to take asthma medication regularly to prevent symptoms and exacerbations [8].

Adolescents with asthma often experience fear, anxiety and shame about their illness and also run a higher risk of developing psychosocial problems than adolescents without asthma [15–17]. It is known that asthma can be difficult to manage in adolescents, due to poor symptom control and low adherence to treatment [18]. Moreover adolescents with asthma often have particular needs that differ from those of children or adults with asthma [19].

Parents and health care professionals may have different perceptions of what is important for achieving good HRQoL [20–22]. Conflicts can also arise regarding different beliefs

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and perspectives on how to treat asthma [23]. Parents may feel that professionals proceed with health care without taking their opinions into consideration [24,25]. To attain asthma control, patients need support from clinicians who pay attention to the patients' experiences of living with an asthma diagnosis [26,27]. Few studies have been published regarding asthma care from a patient perspective. The aim of the present study is to describe the experiences of living with asthma among adolescents with asthma and parents of young children with asthma.

Methods

Selection and description of participants

Four focus group interviews were performed to get a broad and rich insight into the participants' experiences of living with asthma, two with parents of children (2–12 years) with asthma, and two with adolescents (13–18 years) with asthma. Interaction in a group context was chosen to gain a broader perspective, as participants are more likely to express their views after listening to others in a similar situation [28]. Purposeful sampling was used to get rich answers, perspectives and variations of experiences of living with an asthma diagnosis. The homogeneity within each group was created to facilitate group cohesiveness by creating a permissive environment for an open and active discussion [28,29].

After approval from the manager of each child outpatient clinic, one nurse at a clinic north of Stockholm and one nurse at a clinic south of Stockholm identified and listed patients fulfilling the following inclusion criteria:

- Doctor's diagnosis of asthma since at least 2 years, defined in medical records as ICD-10 code (diagnosis code J45 asthma, J45 0 allergy induced asthma, J45 1 not allergy induced asthma or J45 9 unspecified asthma).
- Daily treatment with inhaled corticosteroids.
- Visiting child outpatient clinics at least once a year.

We were provided with lists from the two clinics which included in total 25 adolescents and 25 parents to contact by phone. In each of the four focus group interviews, eight adolescents and eight parents first agreed to participate. In the end, the two focus groups with parents included a total of 11 participants and the two groups with adolescents included a total of 9 participants. Table 1 shows the age, gender and number of participants in each focus group.

Data collection

Data were collected through semi-structured focus group interviews. The interview guide presented in Table 2, consisted of four main open-ended questions related to experiences of living with asthma. These included questions on meeting with health care professionals, self-management, living with asthma and support, with follow-up questions (probes) if necessary, as recommended by Redmond and Curtis [30]. The focus group interviews with parents of children with asthma were performed with a psychologist with extensive experience of qualitative interviews as moderator and one of the authors (MJ) as an observer. The focus group interviews with adolescents were performed with one of the authors (MJ) as moderator and another of the

Table 1. Descriptions of the participants in the focus groups.

	Parents of children with asthma		Adolescents with asthma	
	Group 1	Group 2	Group 1	Group 2
Number of participants	8	3	6	3
Female	4 (mothers)	3 (mothers)	3	1
Male	4 (fathers)		3	2
Age range			13–18 years	13 years

Table 2. Four main questions in the semi-structured interview guide relating to experiences of living with asthma.

Four main questions	Examples
Meeting with healthcare professional	What kind of experiences have you had relating to your meeting with healthcare professionals?
Self-care	How do you take care of your asthma/your child's asthma in daily life?
Living with asthma Support	Explain what it is like to live with asthma? Have you received any form of support? Do you need support?

authors as an observer (EH). The observer's task was to give support and take notes on the interaction in the group. All focus group interviews were conducted in the Child Outpatient Clinic where the participants' follow-ups usually took place. The participants received no compensation for participation in the interviews. The interviews ranged in length from 60 to 90 min and were audio tape-recorded and transcribed verbatim.

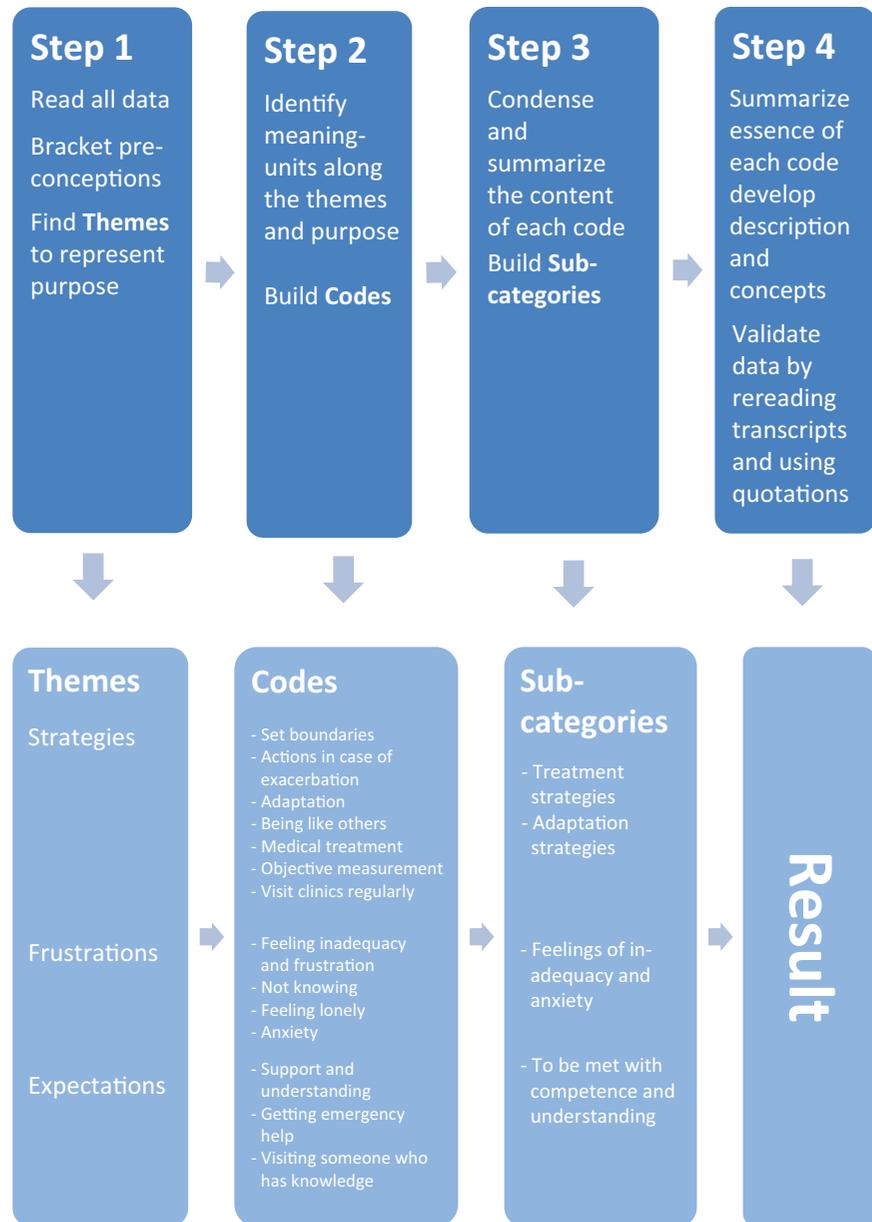
Data analysis

In this qualitative study, the transcribed data were analyzed using Systematic Text Condensation (STC) in accordance with Malterud [31,32]. STC is a descriptive approach, presenting the experiences of the participants as expressed by themselves. The goal of STC is to present vital examples from people's everyday life experiences. Even a limited number of participants can provide sufficient data for analysis [32]. To ensure that the groups' experiences were captured and nothing was missed in the group interaction, the analysis was first conducted separately for each group, and then for the parental groups together and the adolescents groups together. The analysis process followed four steps: finding themes, codes and subcategories and finally summarizing the essence of each code to develop descriptions and concepts, according to Malterud [31,32] as presented in Figure 1. To achieve reliability of the analytical process [33], all steps were first conducted by one of the authors (MJ) and thereafter by the other authors separately. Finally, the process was discussed jointly until agreement was reached. The designated themes, codes and subcategories were compared with the original interviews and appropriate quotes were selected.

Ethical consideration

The study was approved by the Ethics Committee at Karolinska Institutet. All participants were informed that the study was elective and the material would be treated

Figure 1. Analysis process in STC, steps 1–4: finding themes, codes, subcategories and summarize the essence of each code.



confidentially. At the beginning of each focus group session, the participants were asked not to disseminate any information they obtained during the discussion. They were also informed about the aim of the study, stressing that participation was voluntary and that participants could terminate participation at any time.

Results

Parents' and adolescents' experiences of living with asthma were presented as three themes with subcategories. The themes presented were *strategies* (subcategories: treatment strategies and adaptation strategies), *frustrations* (subcategory: insufficiency and anxiety) and *expectations* (subcategory: to be met with competence and understanding).

Strategies

Different strategies was a theme which emerged among both parents and adolescents.

Treatment strategies

Most of the adolescents had developed their own methods of self-management of asthma. Some used medication regularly to prevent exacerbations, while others only used medication when they had exacerbations or before physical activity. Sometimes they just waited until an attack passed.

“I wait until it passes, sometimes I medicate but not very often” (adolescent)

Some adolescents used different reminder techniques as a strategy, for example placing the inhalation device where they would be reminded to use it or using their mother as a reminder. If the adolescents developed asthma symptoms during exercise, friends could urge them to take a break and rest. Friends also warned them of eating things they did not tolerate. Sometimes they shared medication with their “asthma friends”. During pollen season, some of the adolescents with allergies took medication, while others

tried to get more sleep or drank energy drinks in order to become more alert.

When performing regular checkups at the Child Outpatient Clinic the adolescent wanted to perform spirometry tests to check if they were getting better or worse compared with previous tests, i.e. is it still worth go on taking the medication.

“You can see by looking at the curve if it is getting better or worse since the last test” (adolescent)

A treatment strategy for the parents was as soon as asthma symptoms became apparent to immediately give the inhaler device to the children so they not became more impaired and needed to go to the emergency ward.

“As soon I hear sniffing I start to give medication four times a day, you must be as quick as possible so you don't reach the peak” (parent)

Another treatment strategy among parents was to use the Peak Expiratory Flow (PEF) to check their child's asthma symptoms. Some parents used it as a tool to determine when it was time to increase medication, while others never used PEF. Adolescents rarely used PEF to check their asthma.

“You can see from the values when she starts to get worse, then it will only reach a level of 90 when it should be 130 and then you know that it's time to inhale lots of drugs, because you see that an infection is on the way” (parent)

Adaptation strategies

The adolescents strongly wanted to be like everyone else and did not want to be perceived as “different” because of the disease. To achieve this, they used different adaptation strategies.

“I do not think my schoolmates need to know about my asthma, although I am not ashamed of the disease, they have nothing to do with it” (adolescent)

One of the adolescent stated that he always had to adapt to his asthma and realize his limitations in order to decrease symptoms.

Parents expressed that they needed to adapt to their child's everyday life so the child could participate in the same activities as children without asthma, such as sports, playing with friends and attending parties. This adaptation could sometimes resulted in infections for the child and thereby concern on the parents' part.

“When there's a party you stand the risk that your child will get a cold in about three days” (parent)

Adaptation could also mean that parents had to make demands to ensure that their child was treated as well as possible. This could occur in relation to professionals both in health care and in nursery school or primary school. One father said that he had to struggle and communicate well to get staff in health care to understand his child's needs.

“... you have to struggle to get help from someone and you have to be strong and communicate well” (parent)

Frustrations

This was a theme which emerged only among the parents.

Feelings of inadequacy and anxiety

Most of the parents expressed feelings of inadequacy and frustration when their child had exacerbations.

“It's very hard to see when my child becomes very tired and sad from having asthma during the night” (parent)

Another parent said:

“I want the best for my children, so much that it hurts (pointing at her heart) but when they are sick it becomes very difficult to handle” (parent)

A feeling of inadequacy was also expressed among the parents in relation to seeing that their child was ashamed of having asthma.

“It's really hard and tough for me to see that my daughter is ashamed of her illness so she goes into the toilet and hides when she takes her inhaler medication, she feels that she is not like other children, and 9 years is a sensitive age. Other children just stand around and watch her when she takes her medications, it's really hard. I wish that she could meet other children with asthma, now she feels alone” (parent)

The parents' experiences included frustration from not being believed by staff in nursery and primary schools which could mean that their child's asthma symptoms were not taken seriously and the teacher sometimes forgot to give asthma medication to the child. Parents also expressed feelings of not being listened to by teachers when they wanted some changes to take place for their child at nursery and primary school.

In everyday life, the parents felt lonely. They stated that they must be able to manage and treat the child's asthma by themselves.

“When we meet the doctor and nurse we get help, but the child is with us round the clock, we don't know what is bad for him. However, as a parent we must do something so he does not get sick” (parent)

Although the parents tried to be careful and to avoid allergens and triggering factors, their child sometimes experienced asthma symptoms. Parents expressed difficulties in understanding why and when the worsening of asthma appeared. They felt that they did not always know what their child tolerated because they did not get information. The parents were not always sure that their child inhaled in the correct way.

“Every time she had a cold, we gave her the inhaler device and the professional asked if we did it in the right way, but it's hard to know if we inhaled the right way,

because the child took such small breaths at the beginning” (parent)

Expectations

This theme emerged among both parents and adolescents.

To be met with competence and understanding

Parents and adolescents had expectations to be treated by a competent health care professional which did not always occur. They stated that they wanted a health care professional who was competent in the field of asthma and knew how to care for patients with asthma. One example of this problematic lack of competence was that parents felt it had taken too long to achieve the asthma diagnosis for their child.

“It was my daughter, it began when she was six months, then it was 15 times acutely with colds, in and out of hospitals, the doctor said its pneumonia again and prescribed more penicillin, then at age two they said it was not pneumonia, it was asthma” (parent)

Another expectation among parents was the desire to meet doctors and nurses who had both the competence and the possibility to handle acute asthma symptoms. They did not want to be referred to the emergency ward and then have to wait for 2 months to get help from the pediatric specialist at the child outpatient clinic.

“The health care professional says when it is acute you can call us, but then you cannot go to the specialist in asthma care, you still have to go to emergency ward. I want to meet the health care professional who has the knowledge. In the emergency ward they don’t know what it is about and then my son might get the wrong medicine” (parent)

The participants also had expectations that health care professionals should understand and support them regarding asthma management.

“I need help from someone who knows and understands my needs” (parent)

Both parents and adolescents mentioned the support they received from some specific doctors, but they spoke in particular about the support they received from the asthma nurse at the Child Outpatient Clinic. They felt the asthma nurse was a health care professional who had knowledge, competence, and the ability to tailor the treatment as well as give support, i.e. they felt understood.

“I have a direct number to the asthma nurse so I can easily reach her, I could not do it without her support, she calls me up and asks how my child is doing and really supports me all the time” (parent)

“It’s better to meet someone who knows what I need than to be forced to meet ten people and tell them the whole story over and over again” (adolescent)

Having an asthma nurse who could visit the nursery and primary schools to inform teachers about asthma was an important factor for enhancing trustworthiness.

The parents had expectations to get repeated patient education in asthma care.

“Sometimes the health care professional thinks that you have knowledge about the asthma disease and when you get another child with asthma, the professional assumes you already have knowledge, but that isn’t always the case, I think they missed giving repeated information to the same parents” (parent)

Another parent said:

“If you have 10-year-old information maybe it’s not up to date” (parent)

In relation to nursery and primary school, the parents had expectations for improved understanding among teachers for the fact that children with asthma may have different needs than children without asthma. They felt that the school organization must be adapted to suit children with asthma. The parents also wished that school teachers had more knowledge about asthma care and were able to give asthma medication if needed.

“I remember one day... my child was allowed to go to nursery school if they gave her the medicine, but the teacher had forgotten about it” (parent)

Discussion

This focus group study including adolescents with asthma and parents of children with asthma gave us important knowledge about experiences of living with asthma. Living with asthma leads to the development of personal strategies in self-management of asthma. Furthermore both parents and adolescents had expectations by being met by competent and understanding health care professionals. Parents’ expectations were also expressed as a desire that school teachers should have more knowledge and understanding of how to take care of a child with asthma. Adolescents’ and parents’ experiences differed to some extent.

Strength and limitations

One strength pertaining to focus group interviews is the interaction between the participants [34]. This interaction was especially noticeable in the parents’ groups, where they turned to one another, listened carefully when somebody talked, and encouraged what others described. Among the adolescents, it was sometimes difficult to get them to express their thoughts, possibly because they did not know one another. In future research there is a need to get deeper into the adolescents’ life, to uncover what it really means for a teen to live with asthma.

One limitation in this study could be the authors’ long experiences of asthma care; because of their preexisting understanding in the topic area. This could potentially lead to the authors missing something in the interview situation by

taking it for granted. On the other hand an experienced psychologist conducted the first two focus group interviews with parents. He had extensive experience of focus group interviews but less experience pertaining to asthma care. Therefore, one of the authors (MJ) was an observer and could supplement with follow-up questions in the research area as necessary.

A small number of participants can sometimes be regarded as a limitation. However, this is not the case in STC because the systematic steps in the analysis process are aimed at finding themes, codes and subcategories of validity connected to the context. The important thing is to establish rich sample providing coherent stories and the rule of thumb is that the sample should be varied enough to illuminate the aim [32].

Interpretation of findings in relation to previous published work

Focus groups interviews have often been used when describing the experiences of a chronic disease from a patient perspective to attain a deeper understanding in the topic area [28]. A focus group study from UK showed that patients understanding of asthma control extended beyond the usual clinical manifestation to asthma related panic or fear [14]. Related to this result our study also presented new and deeper knowledge of living with asthma from a patient perspective regarding parental frustrations, such as feelings of loneliness, inadequacy and anxiousness.

It is notable that the inclusion criteria in this study stated that children and adolescents should be on daily treatment with inhaled corticosteroids. However, the findings indicated that adolescents had developed their own ways of self-managing. They used asthma medication in different ways; sometimes before exercise or as prescribed, but sometimes they just adapted to the symptoms and waited until they disappeared. There could be many reasons why adolescents are reluctant to take pharmacological treatment.

A review of management of asthma suggested that adolescents deny, hide or ignore symptoms and thereby their need for medication because of their desire not to be different from other adolescents [35]. Furthermore this review indicated the importance of taking into account normal teenage development when treating asthma.

Visits to health care professionals were important for the participants in all focus groups. Adolescents in particular wanted objective measurements of asthma control and used the spirometry test as a strategy to see if they have become impaired or improved. Performance of spirometry tests is an important tool in both the diagnosis and monitoring of asthma and has a high priority in national and international guidelines [7,8]; furthermore, it improves asthma control [36]. A study from Sweden shows that only a minority of children older than 6 years with asthma had ever undergone a spirometry test and only a few had received any patient education [4]. These results have recently been commented by Bush and Fleming [37] suggesting that asthma care requires the KISS approach (Keep It Simple, Stupid). This approach include, get the diagnosis right, give an appropriate level of treatment and make sure the child and family know what is all about,

especially how to use the medication delivery device and eliminate trigger factors in the environment.

In our study, parents expressed frustration and feeling of inadequacy and anxiety regarding how to take care of and give treatment to their child in a correct way. This has also been shown in a review aiming to identify problems associated with the use of pediatric asthma medications [38]. The key issues included a lack of information provided to parents about asthma and asthma medication, and also parental beliefs and fears. This review article indicates that such key issues should be taken into account when developing educational tools.

Having access to a competent General Practitioner (GP), pediatrician and/or asthma nurse for support and understanding was important to almost all participants. A study from Kuethe et al. reported that adherence to asthma treatment could be improved with a strong health care professional–patient partnership [39]. In addition, care provided by an asthma nurse has been reported to be as effective as care provided by a pediatrician or GP in outpatient management of stable childhood asthma [40]. Having access to an asthma nurse in primary care in Sweden has been shown to increase patient knowledge, improve asthma control and reduce costs [41,42].

Parents mentioned a lack of understanding among teachers in nursery and primary schools, meaning they did not understand the specific needs of children with asthma and their asthma symptoms were sometimes not taken seriously. Therefore parents wanted the asthma nurse to visit their child's school and educate teachers about asthma and its consequences for children. In a study from Scotland, teachers found it difficult to distinguish between children who were unable to participate in activities because of their asthma and those who were unmotivated [43]. The authors suggested that this kind of misunderstanding could be decreased if a GP or asthma nurse visited nursery or primary schools and explained what is appropriate and safe in terms of exercise for children with asthma. Recently, the National Board of Health and Welfare in Sweden reported on the situation among nursery and primary schools for children with allergic diseases. This report showed limitations in the school environment as well as in teachers' knowledge about allergic diseases [44]. The Board suggested more education for teachers and improved communication between schools, pupils and their families.

Moreover, both national [7] and international guidelines [8] have stated that asthma management should be developed in partnership between patient and health care professional, in order to be successful. There are four recommended-essential components of asthma management: assessment and monitoring, control of factors contributing to asthma severity, pharmacotherapy and education for a partnership in care [45]. It is important that the patients and the health care professionals agree on and discuss the goals of treatment, something some parents in our study mentioned was lacking.

Conclusions and clinical implications

This study shows that living with asthma leads to the development of personal strategies for self-management.

Moreover both parents and adolescents had expectation of being met by competent and understanding healthcare professionals. Parents' expectations also included having teachers in nursery and primary school with more knowledge regarding asthma care. Developing a partnership between patients and health care professionals with special competence about asthma could be a successful way to improve the care of patients with asthma.

Acknowledgements

We are very grateful to the parents and adolescents who participated in the study and shared their experiences of living with asthma and to the nurses who were very helpful in selecting the participants for the study.

Declaration of interest

The authors declare that they have no conflicts of interest in relation to this article. This study was supported by financial grants from Asthma and Allergy Foundation in Sweden.

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