



## The experiences and needs of parents of children with asthma in coping with the child's disease

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**Abstract.** About 14% of children have asthma, and despite effective treatments, the outcome is not always as expected, with hospitalisation rates remaining high. Parents of children with asthma experience stress as they doubt their ability to cope with the difficult circumstances. Parents complain that they do not have sufficient information on the reduction of factors associated with disease exacerbation. They need knowledge of how to effectively participate in coping with the disease.

The aim of the research is to describe the experiences and needs of parents of children with asthma in coping with the child's disease.

The design of the research is qualitative and descriptive. The data were collected through semi-structured interviews and analysed by an inductive content analysis method. The interviews were conducted in the autumn of 2021. The subjects were found with the help of the Tallinn Children's Hospital staff. Eight subjects participated in the research.

The results of the study showed that the parents' experiences in coping with the child's disease consisted of health-related experiences, life management and material challenges, experiences with relationships, and various support systems. The needs of parents in dealing with the child's disease included the need for various services, the need for information, the need to support the child, and health needs of both the parents and the child.

Parents experienced socio-economic difficulties and incomplete information when coping with the child's disease. For this reason, families should receive support from various specialists and organisations, and the role of nurses is to be a connecting link between families and support services.

**Keywords:** nursing, asthma, coping, child, need, experience.

### 1. INTRODUCTION

Asthma is the most common chronic disease among children. It is estimated that there were 262 million people suffering from asthma in 2019 (Global burden... 2020). Globally, 14% of all children suffer from that disease, and despite the existence of efficient treatment methods, the treatment of asthma does not always give the best possible results, with hospitalisation rates still being high (Fawcett et al. 2017).

If a child suffers from a chronic disease, it has an influence on the family's everyday life. Parents consider

themselves responsible for the management of unexpected situations, which makes the child's chronic disease a huge burden to the family (Borhani et al. 2012). Having a family member with a chronic disease means rearrangements in the family routines to better cope with the disease. Parents' responsibilities include keeping the child away from triggers deriving from the environment or their emotions, which could worsen the asthma attack. In addition to the above, coordinating family and work-related responsibilities, observing the symptoms, and administering treatment are duties that may be a burden for the ill child's carers and have a negative impact on their health (Silva et al. 2015).

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Caring for a child suffering from asthma is a great challenge for the parents – it differs from parenting a healthy child. Depending on the severity of the disease, it is important to have appropriate treatment and maintain correct care for the child. The family may experience social and financial limitations; hence, it is essential to maintain good relations within the family (Smith et al. 2013).

Parents experience difficulties when their child is diagnosed with asthma, especially if it is a toddler. They have suffered from fear and insecurity as they manage their child's asthma during the pre-diagnostic period, when they have often visited the emergency room. Parents are unable to understand the basis of their child's suffering before the official diagnosis. It was found that increased parental stress was linked to the declined psychological adaptation of the carers and the children, and it might worsen the child's health. Additionally, it was found that parents with excessive caring responsibilities were often underinformed about the treatment requirements. It was also found that parental stress was reduced, and following treatment requirements increased when parents and children were encouraged to manage treatment needs together (Fawcett et al. 2017).

Some parents underestimate the severeness of the child's asthma and maladaptation; they refuse to believe that asthma can be controlled, or overestimate their child's physical status (Svavarsdottir et al. 2012). Some parents with a chronically ill child gather information of the child's condition and desire to acquire knowledge of the disease. Efficient disease management includes parents' understanding and knowledge of the condition process and of the appropriate treatment and prevention methods (Chen et al. 2015).

Parents of an ill child with asthma lack sufficient information about reducing the factors linked to disease exacerbation (Callery 2013). They experience mental and psychological stress, anxiety and worrying. They may doubt their ability to cope with challenging situations, and they need knowledge, skills, and readiness to manage their child's condition (Borhani et al. 2012). This topic has been previously studied in other countries (Borhani et al. 2012; Chen et al. 2015; Fawcett et al. 2017), but there is no information about the experiences and needs of parents of children with asthma in the Estonian context.

The objective of the current research is to describe these experiences and needs in the Estonian context.

## 2. MATERIALS AND METHODS

### 2.1. Methodological approaches

The research is qualitative and descriptive. Qualitative research provides rich and detailed description of people's

behaviour and their opinions (Õunapuu, 2014). The authors of the current paper have chosen qualitative approach since it meets the needs of inspecting personal experiences of the participants, using interviews as a data collection method.

### 2.2. Subjects

When selecting subjects for qualitative research, it is important to consider the availability of information on the topic to the participants and their ability to forward this information (DiCicco-Bloom and Crabtree 2006). Inclusion criteria for the current research participants consisted of the following: the subject's child was diagnosed with asthma, the participant is either the mother or father of the child, the subject understands and speaks Estonian, the subject agrees to participate in the study.

Collaboration with Tallinn Children's Hospital was organised to find the subjects. Contact details of the subjects were forwarded to the authors by the representative of the hospital. A convenient sampling method was used to identify the subjects. The authors initially contacted seventeen parents, eight of whom later participated in the study.

### 2.3. Data collection

The authors of the current research have chosen semi-structured interview as data collection method because it allows asking more open questions, which the interviewees can answer the way they prefer. Questions formed by the authors were used for the interviews; these questions were divided into topics based on the research compiled by Dean et al. (2005) and Pishkuhi et al. (2018). The interviews included the following topics: introduction, introductory questions regarding the subject, questions regarding the diagnosed child, questions regarding the family, experiences of the interviewee in coping with the child's disease, needs of the interviewee in the child's disease management, and a summary.

The data were collected in the autumn of 2021. Collaboration was launched with the coordinator in Tallinn Children's Hospital to find the subjects; the coordinator forwarded to the parents the introduction of the study and contact details of the researchers. Following a positive response from the subjects, the researchers contacted them by phone or e-mail to agree a convenient place and time for the subjects to be interviewed.

The interviews were conducted over Zoom, on the phone or by writing emails. Written interviews were arranged because the subjects could not connect on Zoom due to technical problems or find suitable timing for the meetings. The advantage of Zoom video calls was the opportunity for the interviewers to see the emotions

and body language of the subjects during interviewing.

The aim of the research and the subjects' rights were introduced before interviewing and an informed consent form was asked to be digitally signed. A Zoom video call was used in the case of five interviewees, one parent was interviewed on the phone, and two were contacted by e-mail. Interviews were recorded in the Zoom environment while Windows Recording Studio was used for those on the phone. Seventeen parents initially gave their consent for the study, however, only eight of them participated.

The interviews were conducted by using a semi-structured interview plan. The plan consisted of various sets of topics: the first section included introductory questions, the second questions about the subject's experiences, and the third questions of the needs of the subject in coping with the child's disease. The summary part was for the interviewees to add any information they considered necessary. Usually, the interviewing took 20 minutes, the longest lasted 28 minutes and the shortest 15 minutes.

#### 2.4. Data analysis

Content analysis is often used to analyse qualitative data. It can be either inductive or deductive. Deductive content analysis is used when the researcher wants to test the existing data in a new context. Inductive content analysis is used when there are no prior studies of the researched phenomenon (Elo and Kyngäs 2008). The inductive content analysis method was selected by the authors of the current research because there was almost no information on the topic in the Estonian context.

The analysis of qualitative data is conducted simultaneously with data gathering for the researchers to have a uniform understanding of the research results. This repetitive data gathering process and analysis leads to the point in data collection, where there are no new categories, or the same repetitive topics are observed. It is called saturation of database (DiCicco-Bloom and Crabtree 2006). Data saturation did not occur in the current study because some parents that had initially agreed to participate withdrew. An invitation to participate in the study was sent by the Tallinn Children's Hospital staff to all parents of children with asthma registered at the Children's Hospital in the autumn of 2021. However, there were numerous parents who did not express a desire to participate in the study, so the database was not saturated.

Inductive content analysis includes open coding, categorisation, and abstraction. After open coding, the lists of categories are divided as sub- or supracategories (Elo and Kyngäs 2008). All the recorded interviews were

transcribed and marked with codes known only to the researchers (E1, I2 ..., etc.). Next, the researchers read all the interview texts in a detailed way, matching corresponding segments of ideas with research problems. These were then simplified, with similarly simplified expressions formed into substantive codes. Subcategories were created using the received substantive codes. Subcategories were clustered to supracategories, which had similar criteria, and finally two main categories were formed. The process of categorisation is shown in Table 1.

#### 2.5. Ethics and credibility of research

Permission to conduct research was gained from Tallinn Health Care College (No. 1-16/139, issued on 02.06.2020) and approval from the Research Ethics Committee of the National Institute for Health Development (decision No. 396, issued on 07.07.2020). Before the interviews, the subjects completed an informed consent form, which they signed digitally.

Quotes may be used to demonstrate the results and to increase credibility, however, the anonymity of the participants must be ensured (Elo and Kyngäs 2008). For that reason, codes known to the researchers only were used for presenting quotes in the current research.

Transcriptions of the interviews and sound files were preserved in the computers of the researchers, protected with passcodes and available to the authors of the research only. After completing the research paper, all the transcriptions and audio files were deleted.

### 3. RESULTS

#### 3.1. Socio-demographic data

Four mothers and four fathers participated in the study. The mean age of the subjects was 42, the youngest being 31 and the oldest 49. Seven parents were married and one divorced. Three adults had higher education and five had vocational secondary education. Five parents were employed, one had partial incapacity to work and received social benefits for the impairment, one was temporarily unemployed, and one was on maternity leave. The subjects' religious beliefs varied: two parents were orthodox, two replied that they were believers, three parents had no religious views, and one did not want to reply to this question.

#### 3.2. Parents' experiences in coping with the child's disease

The main category 'Parents' experiences in coping with the child's disease' is formed of substantive codes, which

**Table 1.** Process of categorisation

Segment of idea in database	Substantive code	Subcategory	Supracategory
<p><i>'We always spent lots of time together with our daughter and son...'</i></p> <p><i>'We used to walk together, rode a bike...'</i></p> <p><i>'The child did not go to kindergarten due to illness...'</i></p>	<p>Living conditions stayed the same</p> <p>Living conditions were totally changed</p> <p>Child could not attend kindergarten</p>	Experiences linked to changes in living conditions	Experiences linked to challenges in living conditions
<p><i>'Since I have partial employment incapacity and impairment benefit...'</i></p> <p><i>'Family's financial situation is not the best still...'</i></p>	<p>Moderate financial difficulties</p> <p>Worsening of financial situation</p>	Experiences linked to financial problems	
<i>'Maybe psychological or specialist's help...'</i>	<p>Psychological help</p> <p>Services of a specialist</p>	Need for specialist services	Need for various services
<p><i>'Even if there is a child minder...'</i></p> <p><i>'To be possible to hire a babysitter.'</i></p>	<p>Partial reimbursement of costs of the child minder</p> <p>Possibility to hire a child minder</p>	Need for child minding services	

were arranged into 16 subcategories, and the latter into five supracategories (Table 2).

### 3.2.1. Experiences linked to challenges in living conditions

Regarding financial problems, it was highlighted that the budget was tight, and the mother had to hire a babysitter. *'I was forced to hire a babysitter in order to have a job.'* *'The family's financial situation is still not good. Sometimes we experience moderate financial difficulties.'*

Some parents emphasised there were no changes in their living conditions.

*'It is easy in our case because we did not have a great change.'*

Parents emphasised that they must administer medication to their child regularly and carry an inhalator with them.

*'You simply have to have regular treatment.'*

*'We take an inhalator everywhere.'*

Regarding adaptation, parents had various experiences. One family thought the adaptation could be done well and they managed to do it.

*'We adapted step-by-step; it was difficult at the beginning – we were scared...'*

One family adapted smoothly and without much stress. However, it happened because there was another child in the family with the same diagnosis, so it cannot be generalised to other families.

*'It was stress-free with the second girl already.'*

It was found that parents had a lack of information about the new situation. Some parents were unaware who to ask for help or advice. After confirmation of the diagnosis, parents had lots of questions regarding coping with the disease.

*'We had no idea how to act at the beginning. It was difficult to understand what to do at the beginning.'*

*'We had the question what if we did something wrong or we didn't notice the asthma attack immediately.'*

### 3.2.2. Experiences in diagnosing the disease

It was communicated that the child's disease had not been noticed on time and initially misdiagnosed.

*'General practitioner's misdiagnosis resulted in administering many antibiotics to the daughter, which caused even more health problems.'*

**Table 2.** Parents' experiences in coping with the child's disease

Subcategory	Supracategory	Main category
Experiences linked to financial problems Experiences linked to changes in living conditions Experiences linked to adaptation Experiences linked to receiving information	Experiences linked to challenges in living conditions	Parents' experiences in coping with the child's disease
Negative experiences in diagnosing the disease Positive experiences in diagnosing the disease	Experiences in diagnosing the disease	
Experiences linked to parents' physical health Experiences linked to parents' mental health Experiences linked to child's health problems	Experiences linked to health	
Positive experiences linked to family relations Negative experiences linked to family relations Positive experiences linked to healthcare staff Negative experiences linked to healthcare staff	Experiences linked to relationships	
Experiences linked to family support Experiences linked to various support organisations Experiences linked to specialists	Experiences linked to various support systems	

### 3.2.3. Experiences linked to health

Regarding parents' physical health, sleeping disturbances and exhaustion were highlighted.

*'Sleeping disturbances occurred, lack of sleep...'*

*'Sure, in me /.../ tiredness, exhaustion.'*

Moreover, there was a parent that experienced worsening of previous health problems.

*'I had chronic health problems that were with me in the past, too.'*

### 3.2.4. Experiences linked to relationships

It was described that the relations between parents had not changed, family members got along well, and some mothers did not have problems in family relations.

*'... have not changed.'*

*'Everyone gets along well.'*

Some parents highlighted those relationships becoming tense with many arguments happening. Also, mutual support was lost, and the grandparents of some families were worried.

*'... tension. There were many quarrels and we lost each other's support.'*

*'My parents are very worried.'*

*'Child's father moved out.'*

Some interviewees replied that they had had much positivity linked to healthcare staff, especially at pulmonologist's appointments.

*'Specialist pulmonologist prescribed appropriate medications.'*

*'We had the right doctor, good medications, procedures and examinations.'*

*'I really liked the doctor's friendly attitude.'*

Vague answers by doctors as well as visiting several doctors were mentioned.

*'Doctors' replies were rather vague.'*

*'We simply went from one doctor to another.'*

### 3.2.5. Experiences linked to various support systems

Parents emphasised the following: relatives' help in baby-sitting the child, help from the family, support from the family being important both emotionally and physically,

all family members supporting each other.

*'Luckily relatives helped, they babysat the elder child.'*

*'I got help from people close to me.'*

*'... emotionally, but they also helped to babysit the child and take care of the other child.'*

Parents highlighted the essential roles of occupational therapy, kindergarten, various hobby groups, and the organisation 'Rajaleidja' ('Pathfinder'). 'Rajaleidja' is an all-Estonian network that offers free study counselling for adults who support children in their education – parents, teachers, support specialists, etc.

*'I also visit occupational therapy with them.'*

*'We went to "Rajaleidja" to keep them in the kindergarten...'*

*'This year new hobby groups were offered such as football, etc.'*

Regarding different specialists, an occupational therapist and a special teacher were mentioned.

*'There are really pleasant occupational therapists.'*

*'Now a special teacher is involved, they go to hers, too.'*

### 3.3. Parents' needs in coping with the child's disease

The main category 'Parents' needs in coping with the child's disease' is formed of substantive codes, which were categorised into 12 subcategories, which themselves formed six supracategories. 'Parents' needs in coping with the child's disease' is explained in Table 3.

**Table 3.** Parents' needs in coping with the child's disease

Subcategory	Supracategory	Main category
Needs linked to financial problems Needs linked to living conditions	Needs linked to challenges in living conditions	Parents' needs in coping with the child's disease
Needs linked to parents' physical health Needs linked to parents' mental health	Needs linked to parents' health	
Needs linked to child's physical health Needs linked to child's mental health	Needs linked to child's health	
Need for specialist services Need for child minding services	Need for various services	
Need for more information Need to understand the disease	Need for information	
Need to maintain the child's welfare Need to inform the child of the disease	Parents' need to support the child	

### 3.3.1. Needs linked to challenges in living conditions

Parents highlighted the family's worrying financial situation. *'Need for higher income, so that we could pay for help.'* *'... so, the greatest need in our family would be to have a better financial situation.'*

### 3.3.2. Needs linked to parents' health

It was mentioned that parents needed quality sleep, to have a rest and some physical help. Parents are tired and their sleep is disturbed. *'... sleep, quality sleep.'*

*'It is very difficult. Physical help is needed.'*

The need to relax with the spouse was highlighted. One father was worried about changes in the spouse's mental health.

*'Maybe the spouse also needs to be more attentive to her health.'*

### 3.3.3. Needs linked to child's health

Needs linked to the child's physical health were associated with prevention.

*'... to think of prerequisites of asthma and to create conditions to prevent and avoid the symptoms.'*

Regarding the child's mental health, noticing the changes and being with the child when they are scared were considered significantly important.

*'... you know, to notice relevant changes and to be with the child when they are afraid.'*

*'The child felt helpless, panic attacks escalated ... Calm and support the child.'*

### 3.3.4. Need for various services

Regarding various services, the need for psychological help and specialist services as well as different therapies were mentioned.

*'... maybe psychological help or specialist services.'*

*'Maybe different therapies could help.'*

Mention was made of a need for partial reimbursement of babysitter costs and to have an opportunity to hire a permanent child minder.

*'There is even a need to get compensation for some money given to the babysitter.'*

### 3.3.5. Need for information

It was mentioned that reliable information sources were essential as well as trustworthy doctor's examinations. It was informed that doctor's answers were too minimalistic. Some parents have complained of a lack of information and its accessibility.

*'I still need trustworthy sources for information.'*

*'I even do not know now if and which additional services a child with asthma could get.'*

Parents said that it was necessary to understand the nature of the disease; a parent does not have an overview of the disease and they have no actual information about the disease.

*'The number one is information and understanding of this disease.'*

*'I still have no overview of...'*

### 3.3.6. Parents' need to support the child

One of the parents highlighted that it was essential for the child to be themselves. It was also mentioned that the child should live a full life without any limitations.

*'Don't limit the children in that age, because they...'*

*'You have to let the child be who they are...'*

The parents highlighted the importance of explaining the nature of the disease to the diagnosed child and other members of the family.

*'If the child is older, they should be explained...'*

## 4. DISCUSSION

Not many studies have been conducted regarding parents' experiences and needs in coping with the disease of the child suffering from asthma. If nurses understood those needs better, it could be the basis of a more patient-centred and effective nursing care. The results of the present research allow for the provision of such care, including helping the parents.

The current research found that parents had both positive and negative experiences about diagnosing the disease and communicating with healthcare staff. It was observed that one family had adapted to the diagnosis smoothly and with almost no stress. However, it happened since there was another child in the family with the same diagnosis, so the result cannot be generalised to other families. Rather, some parents experienced a difficult diagnosis process. Fawcett et al. (2017) have found that parents regularly encounter difficulties in receiving asthma diagnosis. It has also been found that carers often experience fear and insecurities when managing their child's asthma, and frequent visits to the emergency room are common. The research of the current authors revealed one of the participants' thoughts that better knowledge of the disease would have been helpful in caring for the child more efficiently. Most participants highlighted the amount of time spent in hospital and the frequency of doctor's visits. Therefore, the diagnosis process of the disease may last longer and lots of time is spent in hospital settings, especially if the child is a toddler.

According to Silva et al. (2015), having a chronic disease in the family requires family members to have changes in routines to help coping with the disease. The authors of the current research found that parents followed a certain routine, which included regular administration of medications and observation of symptoms. One of the participants replied that it was more difficult to coordinate family and work-related duties because she had to hire a babysitter to manage financially at that time.

Chen et al. (2015) have reported that some parents collect information about the child's condition and wish to gain more insight about the disease. Parents' knowledge of the disease process is an effective way to cope with the disease. It was found in the current research that one of the parents did not have a clear understanding about the seriousness of the disease and wanted to consult more reliable sources. The parents were unaware whether the child would recover in the future or not. Callery (2013) has pointed out that many parents whose child has asthma do not have sufficient information about the reducing factors related to the exacerbation of the disease, and due to the lack of knowledge they are unable to prioritise the importance of following the treatment plan. The main problem is the lack of information necessary to help the child.

The study conducted for this research revealed that parents would like to be more informed of how to prevent the disease and how to alleviate it. They would like to be aware of the ways to reduce factors worsening it and to specify on time how to administer treatment to the child. Therefore, initial information is not enough for parents, and if a parent is anxious, they will memorise less of the received information. Hence, the authors of the current research share the message that nurses and other healthcare staff should spread reliable information in a way that parents would understand it. It was surprising for the authors of this paper that parents required more information specifically from the doctor and not from other healthcare employees, e.g., nurses, who saw the child more often. Nurses play an important role in supporting the family on the journey related to the child's disease.

Borhani et al. (2012) emphasised in their research that parents of children with asthma experienced mental and psychological stress, anxiety, worrying and suspiciousness first of all in their abilities to manage extreme situations. The authors of the current paper found that parents had acquired various mental and physical health problems. All the interviewees had experienced chronic fatigue and decline in sleep quality. Also, general emotional tension, sadness, lack of energy, burnout, and depression were complained of. This research further confirmed that adaptation added emotional tension and changes in living conditions. Challenges were experienced in the family's financial situation, adaptation to the disease, and receiving information. The interviewees mentioned that the child's

diagnosis changed the general financial situation of the family. Some parents reported moderate financial difficulties, yet not all participants experienced them. Smith et al. (2013) have written that for families with social and financial limitations maintaining good family relations is essential. Good relations help to endure financial problems but cannot solve them all. Compared to other countries, social support system has bottlenecks in Estonia. Parents of children with chronic diseases are often in a difficult financial situation, which impairs the parents' ability to cope with the child's disease. All participants of this research highlighted the importance of each other's support in the family. One of the interviewees had had a negative experience in family relations, which resulted in one parent moving out of their home. The authors of this paper agree that families differ from each other a lot. Every individual family has various relations among them; therefore, it is really important to support each other in a family.

The results and knowledge gathered within this research are planned to be used practically to improve the collaboration between healthcare employees and parents, find solutions to problems experienced by parents, and provide support and help considering parents' needs. This work could draw attention to the fact that the presence of a chronic disease in one child also affects other family members. The authors of the research find that more attention should be paid to childhood asthma and its influence on the whole family life. To implement the results of the research in practice, the authors will introduce them to nurses, doctors and specialists from different organisations encountering children with asthma and their families in their daily work. Presentations and discussion circles will be arranged to become aware of bottlenecks and find solutions for improving the families' coping with the child's chronic illness.

## 5. CONCLUSIONS

The research demonstrated that parents' experiences in coping with the child's disease were linked to living conditions and financial situation, diagnosis of the disease, changes in health, relations, and various support systems. Parents mentioned that their budget was tight due to financial problems. Lack of information and correct diagnosis were considered as a major problem. Adaptation should be achieved continuously and smoothly. Experiences related to changes in health included experiences of parents' mental and physical health and experiences linked to child's health problems. It was highlighted that parents lacked sleep, they were exhausted and tired. It is an emotional burden if their child is continuously ill. Relations with healthcare staff and family



members were described in the study. Negative and positive sides of family relations were mentioned. Positive sides included everyone getting along well without problems. Negative sides were quarrels, tension, loss of mutual support, separation of parents, and worrying of grandparents. Various support systems were of major help, consisting of family, support organisations and specialists (occupational therapist and special teacher).

Parents' needs in coping with the child's disease were linked to living conditions, parents' and child's health, need for various services, need for information, and need for the parent to support their child. Parents felt the need for additional income to alleviate the financial burden. Regarding health, the greatest need, however, was to get enough rest. Above all, parents needed mental support – a psychologist or a counsellor as well as permanent child minder services to support the family. The need for information was one of the most essential needs of the parents regarding coping with their child's asthma. Parents lacked necessary information about the disease and the answers of healthcare employees were short. Therefore, they required more reliable and understandable information and regular check-ups. To support the child, parents needed the skills to maintain the child's welfare and inform the child of their disease. Parents found that the child should live fully and be able to be a normal child. Moreover, the nature of the disease should be explained both to the diagnosed child and other members of the family.

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## **Astmat põdevate laste vanemate kogemused ja vajadused lapse haigusega toimetulekul**

Kadri Kõöp ja Mare Tupits

Ligikaudu 14% lastest põeb astmat ja vaatamata tõhusale ravile ei ole tulemus alati ootuspärane ning haiglaravi määr on endiselt kõrge. Astmat põdevate laste vanemad kogevad stressi ja kahtlevad oma võimetes keeruliste olukordadega toime tulla. Vanemad kurdavad, et neil ei ole piisavalt teavet haiguse ägenemisega seotud tegurite vähendamise kohta. Nad vajavad teadmisi, kuidas haigusega toimetulekus tõhusalt osaleda.

Uurimistöö eesmärk on kirjeldada astmat põdevate laste vanemate kogemusi ja vajadusi haigusega toimetulekul.

Uurimistöö on kvalitatiivne ja kirjeldav. Andmed koguti poolstruktureeritud intervjuu abil ning analüüsiti induktiivse sisuanalüüsi meetodil. Intervjuud viidi läbi 2021. aasta sügisel. Uuringus osalenud lapsevanemad leiti Tallinna Lastehaigla personali kaasabil. Uurimistöös osales kaheksa uuritavat.

Uurimistöö tulemused näitavad, et vanemate kogemused lapse haigusega toimetulekul hõlmasid tervisega seotud kogemusi, elukorraldust ja materiaalseid väljakutseid, kogemusi suhetega ning erinevate tugisüsteemidega. Vanemate vajadused lapse haigusega toimetulekul näitasid puudust erinevate teenuste järele: teave, lapse toetamine ning nii enda kui lapse terviseteeve.

Vanemad kogesid sotsiaalmajanduslikke raskusi ja teabepuudust lapse haigusega toimetulekul, seega peaksid pered saama tuge erinevatelt spetsialistidelt ja organisatsioonidelt ning õdede roll on olla ühendav lüli perede ja tugiteenuste vahel.