



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

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**Abstract.** The most common rheumatological disease in children is juvenile idiopathic arthritis (JIA). At the beginning of the disease, the predominant emotions of the parents are growing anxiety, fear, confusion and denial of the disease. In Estonia, parents of children suffering from JIA do not receive enough support and information about their child's health problem or social benefits and services.

The aim of the thesis is to describe the experiences and needs of parents of children with JIA 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 the inductive content analysis method. The interviews were carried out in 2021 with eight subjects participating in the research.

The authors of this research found that the parents' experiences in coping with the child's disease consisted of adaptation to the disease, feelings of the parents regarding their child's situation, family relations, nature of the disease and various support mechanisms. At the beginning of the disease, fear and anxiety were experienced. The needs of parents were related to supporting the child's coping with the disease, the treatment process and school requirements. In order to do that, parents sought psychological help. Regarding the treatment process, the parents' desire to cooperate with healthcare workers grew as the disease exacerbated. More understanding was needed from teachers regarding the obstacles and limitations due to the child's disabilities.

In conclusion, when adapting to the child's disease, parents experienced both positive and negative feelings as well as a lack of information. Families should feel supported by healthcare professionals, local municipality and educational institutions.

**Keywords:** juvenile idiopathic arthritis, child, parent, experience, need, coping.

### 1. INTRODUCTION

Juvenile idiopathic arthritis (JIA) is the most common chronic rheumatological disease in childhood, characterized by chronic arthritis beginning before the age of 16, persisting for at least six weeks, and having no other identifiable cause. Incidence of the disease varies from 0.83 per 100 000 children in Japan to 23 per 100 000 children in Norway. Pruunsild et al. reported a 3.5-fold increase over three consecutive years in Estonia (Oberle et al. 2014, 379–393). In Estonia, it has been found that the highest incidence per

100 000 children is in the age group of 10–14 years (Tervisestatistika ja...).

After confirmation of the diagnosis, it is very important for the parents to understand the nature of the disease and its influence on the child's health. Children with a chronic disease are more dependent on the parents: they need more help, attention and a caring attitude, which increases the parents' responsibilities significantly (Laanemets 2013, 11). It is typical that the child's primary caregivers are the parents, who have several assignments to complete such as administering medications and injections, taking the child to the doctor's appointments, renewing prescriptions and buying medications, using painkillers (Cassidy et al. 2010, 163).

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Usually, parents of the child with a chronic disease are more anxious than parents of healthy children; however, in the case of parents of children with JIA, two types can be distinguished: parents who are more anxious and parents whose adaptation skills are similar to those of healthy children. A significant finding shows that the expected workload by parents of taking care of their child correlates more with their own emotional coping skills than with the intensity level of their child's disease (Bruns et al. 2008; Anthony et al. 2011, 53). The parents who are more understanding of their child's disease and more aware of their role as caregivers are not very anxious. In addition, these parents adapt to the new situation more effectively and have less symptoms of depression (Ramsey et al. 2013, 285). Mothers of chronically ill children in Estonia have more stress and other psychological health problems, such as depression and anxiety, compared to mothers whose children are healthy (Asula 2014, 8–12, 23).

Both children and their parents may suffer from stress, anxiety, depression and other mental disorders. Children can be worried that the diagnosis may have been the result of their inappropriate behaviour, whereas their parents may be disturbed because they think the child's disease could be related to something they have done wrong (Caring for ... 2018, 41–42). Parents have more serious problems when the disease is diagnosed for the first time and at the beginning of the treatment; they face the unknown and look for resources to manage it. The disease can influence both marital and sibling relations (Yuwen et al. 2017, 23–29). Social support relieves parents' stress and social support programmes significantly reduce the mental health problems of these parents (Mawani et al. 2013). Gheibzadeh et al. (2020) have found in their research that parents in a better economic situation cope more effectively with their child's disease.

Interviews have revealed that one of the greatest challenges while caring for the child with a rheumatic disease is pain management. If treatment helps to control the pain, life is almost normal; however, if the pain is more acute and out of control, parents often experience emotional stress (McNeill 2004, 528).

A whole team, including a paediatric rheumatologist, ophthalmologist, orthopaedist, child psychiatrist and physiotherapist, deals with the treatment of the disease. The main goals of the treatment are to suppress the activity of the disease, normalise joint function, preserve normal growth and prevent long-term joint damage (Barut et al. 2017, 90–101).

Parents' contact with hospital setting usually occurs by visiting the doctor, who mostly completes the treatment plan, or by visiting the nurse, who helps to find solutions to their daily problems and supports the completion of various life stages. The nurse can offer the family counselling on diverse topics: how to understand the nature of the disease and how to talk about it with their child, what

the causes are for the occurrence of pain, how to assist pain treatment, how to communicate with various health-care facilities, how much rest is needed to avoid worsening of the disease (McKeever 2015). The problem is that the parents of children suffering from JIA do not receive enough support – neither information about their child's health problem nor social benefits and services in Estonia. (Laanemets 2013, 2–3).

The objective of the current research is to describe the experiences and needs of parents of children with juvenile idiopathic arthritis in coping with their child's disease in Estonia.

## 2. MATERIALS AND METHODS

### 2.1. Methodological approaches

The research is qualitative and descriptive. Qualitative research is used when little is known about a topic or phenomenon and there is a desire to learn more. It is commonly used to understand people's experiences (Munhall 2012, 146–147). The authors of the current paper have used interviews as a method for data collection.

### 2.2. Subjects

Inclusion criteria for the subjects in this research were the following: the subject's child has been diagnosed with JIA, the subject is either a mother or a father of the child, the participant speaks and understands Estonian, the participant agrees to take part in the research.

Collaboration with Tallinn Children's Hospital was organised to find the subjects. Initial agreement with the subjects was signed by a representative of the hospital. Contact details of the subjects were forwarded to the authors by the representative of Tallinn Children's Hospital. Eight subjects participated in the study. The youngest participant was 38 and the oldest 46, with the average age of 42.

Three participants were married and five had a non-marital relationship. Four subjects had completed vocational secondary education, three had higher education and one had basic education. The youngest child at the time of the initial diagnosis was 1.5 years old and the oldest was six. The average age of children on diagnosing JIA was four.

### 2.3. Data collection

Semi-structured interview as a data collection method was the basis of the current research. Questions for the current research's interview plan were based on studies conducted by Ahmadi Pishkuhi et al. (2018) and their surveys, which consist of various sets of topics. The first part of the

interview included introductory questions, the second part questions about the subject's experiences and the third part 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.

Before conducting the interview, the aim of the research and the subject's rights were introduced to the interviewees, who were then asked to digitally sign an informed consent form. Although the interviews were planned to last for up to an hour, their actual length varied considerably from the shortest of 13 minutes to the longest of 72 minutes. The interviews were conducted in the most suitable environment for the interviewee. All the interviews were recorded using various recording devices simultaneously (smartphone, laptop and voice recorder). After the first three interviews, a considerable number of answers given by the subjects started to recur. Children of the interviewees mainly experienced mild symptoms; therefore, the answers were similar to a great extent and the data resulted in saturation.

#### 2.4. Data analysis

Qualitative content analysis method, based on non-numerical features and using inductive approach, was applied in data analysis. The approach was utilised because more information was needed about the phenomenon.

Inductive content analysis uses abstraction process to reduce the data and for categorisation, so that the researchers can answer the research problems by terms, categories or topics (Kyngäs 2019, 9).

To analyse the data, first the audio files were transcribed and marked with codes known to the authors only (E1., I2. ..., etc.). After that, the recordings were played and the transcribed texts read simultaneously to get a better overview of the collected material. Essential parts for the research were highlighted in the transcribed texts while the rest of the text was excluded. Substantive codes were written based on segments of the texts; these were categorised as subcategories, which were grouped as a supracategory consisting of two main categories. The process has been demonstrated in Table 1.

#### 2.5. Ethics and credibility of the research

Permission to conduct research was gained from Tallinn Health Care College (No. 1-16/139, issued on 02.06.2020) and approval from Research Ethics Committee of the National Institute for Health Development (decision No. 396, issued on 07.07.2020).

No names of the subjects were used in representation of the data; segments of the texts were numbered based on the queue of interviews. Full texts of the interviews will not be published nor uploaded on the internet for

**Table 1.** Categorisation process

Segment of idea from database	Substantive code	Subcategory	Supracategory
<p>'... we had slight understanding of this disease already.'</p> <p>'... must cope.'</p> <p>'... we have adapted and accepted in General.'</p>	<p>Understanding of the disease</p> <p>Reasonable attitude towards the disease</p> <p>Disease acceptance</p>	<p>Conditions supporting adaptation</p>	<p>Experiences linked to adaptation</p>
<p>'... one will never adapt to anything like that...'</p> <p>'... I did not have enough information and that I should look for it myself.'</p> <p>'... it was difficult at the beginning because the child was so young, it was very tough.'</p> <p>'... that family physicians do not know a lot about this disease.'</p>	<p>Difficulties to adapt</p> <p>Insufficient information</p> <p>Difficult beginning</p> <p>Insufficient knowledge by family physicians</p>	<p>Conditions not supporting adaptation</p>	

public use. Transcriptions of the interviews and sound files were preserved in computers of the researchers, which were 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. Parents' experiences in coping with the child's disease

The main category 'Parents' experiences in coping with the child's disease' was formed by topical substantive

codes, which were arranged into 12 subcategories. These 12 were arranged into five supracategories, which addressed the experiences linked to adaptation, feelings, nature of the disease, family relations and various support mechanisms. Parents' experiences in coping with the child's disease are shown in Table 2.

**Supracategory 'Experiences linked to adaptation'** was formed of two subcategories: experiences supporting adaptation and experiences not supporting adaptation.

**Experiences supporting adaptation:** parents had experienced that, in order to adapt to the disease more successfully, they had to agree to and accept the disease and have a reasonable view of the disease.

*'... we have adapted and accepted, in general.'*  
*'... must cope.'*

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

Subcategory	Supracategory	Main category
Experiences supporting adaptation Experiences not supporting adaptation	Experiences linked to adaptation	Parents' experiences in coping with the child's disease
Experiences linked to negative feelings Experiences linked to positive feelings	Experiences linked to feelings	
Experiences linked to prognosis of the disease Experiences linked to availability of information	Experiences linked to the nature of the disease	
Experiences linked to improved family relations Experiences linked to stability of family relations Experiences linked to family support.	Experiences linked to family relations	
Experiences linked to support from healthcare staff Experiences linked to support provided by local municipality Experiences linked to financial support	Experiences linked to various support mechanisms	

Parents mentioned that they had slight understanding of the disease already at the moment of the diagnosis because this disease had been running in the family.

*'... we had slight understanding of this disease already.'*

**Experiences not supporting adaptation:** parents had experienced that it was difficult to accept the disease, partially due to the child's age when it was diagnosed.

*'... one will never adapt to anything like that...'*

*'... it was difficult at the beginning because the child was so young, it was very tough.'*

Parents had experienced that a major issue was the lack of information. Despite the information gained from their doctor, it was not considered sufficient, and more detailed information was desired about the disease. Many participants highlighted their need to look for information at the beginning of the diagnosis, partially because family physicians lacked knowledge regarding the disease.

*'There is not a lot of information.'*

*'... I did not have enough information and I had to look for it.'*

*'... that family physicians do not know a lot about this disease.'*

**Supracategory 'Experiences linked to feelings'** was formed of two subcategories: experiences linked to negative feelings and experiences linked to positive feelings.

**Experiences linked to negative feelings:** most parents had experienced that adaptation to the disease was linked to shock, fear, fright of the unknown.

*'... there was fear of the unknown.'*

*'... but rather yes, we needed adaptation time, of course, it was difficult and sad...'*

*'... either a fear or rather a shock; it was such an initial fright.'*

One parent mentioned that among other emotions anxiety occurred, partially because of hard sleepless nights. Another mother, however, mentioned worrying and anxiety due to worsening of their child's health status.

*'... serious anxiety occurred sometimes...'*

*'... I am more worried and anxious maybe myself...'*

**Experiences linked to positive feelings:** parents had found that accepting the disease and an optimistic attitude helped to influence the course of the disease positively. Some parents thought these children should be treated the same way as they had been before, as if they were healthy.

*'... the attitude should be as if they were a common healthy child.'*

*'... I find you should not keep these children away from everything and protect them so...'*

**Supracategory 'Experiences linked to the nature of the disease'** was formed of two subcategories: experiences linked to prognosis of the disease and experiences linked to availability of information.

**Experiences linked to prognosis of the disease** described how the possible prognosis caused worrying by the parents.

*'... since the disease is progressive, of course Mum worries a lot...'*

*'... I had no idea, I do not know what the prognosis is, the prospects, which treatment.'*

**Experiences linked to availability of information** were described as positive by one of the subjects.

*'... the doctor is always there for us as a person – it is not simply about the disease, but they immediately refer and answer.'*

**Supracategory 'Experiences linked to family relations'** was formed of three subcategories: experiences linked to improved family relations, experiences linked to stability of family relations and experiences linked to family support.

**Experiences linked to improved family relations:** it was described that after confirmation of the diagnosis, family relations had improved. Some interviewees highlighted the uniformity of the family because of the child's welfare; they thought that difficulties resulting from the disease brought the family members closer to one another.

*'... rather no, but we still stick together so that the children would feel good about themselves.'*

*'... these difficulties and serious matters more like unite people...'*

**Experiences linked to stability of family relations:** it was described that the existence of the disease had no negative impact on relations with the spouse and the parents' relationship was still as good as before.

*'No, it has not changed, we have always got along well with my husband.'*

*'... everything is good in our family.'*

*'... I think that very well, we live like a normal family...'*

*'... it has not changed.'*

**Experiences linked to family support:** similar aspects were mentioned when talking about experiences linked to family support regarding the relations between two parents and the disease management:

*'Mutual support was sufficient for us; we did not have to look for help outside the family...'*

*'... let's put it this way: we had to cope alone...'*

**Supracategory 'Experiences linked to various support mechanisms'** was formed of three subcategories: experiences related to support from healthcare staff, experiences linked to support provided by local municipality and experiences linked to financial support.

**Experiences related to support from healthcare staff:** this subcategory described the experiences of several parents how their doctor had helped them to cope with the disease.

*'Definitely the doctor; and yes, we have researched ourselves, too; and friends and acquaintances whom we know to have experience of the same disease...'*



*‘... that I received somehow quick and very professional help.’*

*‘... the doctor also being very supportive, very calm, that “let’s look and observe, and if something else would work out, then we might change the treatment plan”.’*

Some participants highlighted the availability to also communicate with their family physicians or paediatricians to have necessary treatment on time.

*‘I can be in touch /.../ existing paediatricians, I can /.../ have necessary examinations, too...’*

*‘... I have reached doctors somehow quickly.’*

There were subjects who highlighted the courtesy of doctors and their empathy in conversations as well as the assurance that they can always receive necessary help.

*‘... doctors have always been very courteous and probably Mum knows which questions to ask.’*

*‘Very constructive and relevant conversations and I always get help; they are very helpful.’*

**Experiences linked to support provided by local municipality:** here different situations were described.

*‘... the municipality of our district has offered a camp for us and we have been there twice. Summer camp for children with special needs...’*

*‘Unless you go to the local municipality and ask for a benefit, they will not provide it themselves without you asking...’*

**Experiences linked to financial support:** one participant highlighted the mildness of the disease in their family, which has made it possible not to utilise social monetary benefits. Medications are quite affordable, and they have never needed an aid card that would provide a discount on buying assistive devices.

*‘... does not influence a lot ... medications are quite cheap ... there are no other costs kind of...’*

*‘We have not needed assistive devices a lot ... we have this aid card ... we bought a wheelchair from Invaru shop with discount...’*

A participant highlighted the sufficiency of their family resources, which enables them to buy assistive devices for the child, if necessary.

*‘... you say I might get help from the state, then I would rather give this opportunity to someone that needs it because we have all the assistive devices we need. It also has some negative symbolic taste for me if I need the state’s help.’*

**3.2. 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 are categorised into six subcategories and these to three supracategories, which consist of the needs regarding supporting the child’s coping, the treatment process and school requirements.

Parents’ needs in coping with the child’s disease are explained in Table 3.

**Supracategory ‘Needs linked to supporting the child’s coping’** was formed of two subcategories: needs linked to psychological coping and needs linked to support services.

**Needs linked to psychological coping** highlighted a parent’s description, which revealed that no one had offered their family options for getting psychological help.

*‘... someone should refer us to look for help, the doctor or someone. No one has ever mentioned it to us.’*  
*‘... I think if we had searched back then, maybe we would have got some help, but since there was no referral, we did not find it. But I think that the state would have provided that help back then, too, but I am unsure if really.’*

One participant needed the services of a psychiatrist after confirmation of the child’s diagnosis.

*‘It would be nice if after the diagnosis confirmed by the doctor you would not emotionally break a person inside but refer them to the psychiatrist.’*

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

Subcategory	Supracategory	Main category
Needs linked to psychological coping Needs linked to support services	Needs linked to supporting the child’s coping	Parents’ needs in coping with the child’s disease
Needs linked to medications Needs linked to worsening of the disease	Needs linked to the treatment process	
Needs linked to assistance in studies Needs linked to communication with the school	Needs linked to school requirements	

**Needs linked to support services:** one parent highlighted the lack of support by the state to children with special needs. The amount of social benefits was very low while the costs were significantly higher:

*'It was very difficult to cope at the beginning because the state did not help children with special needs, and we had to hire a nanny and received neither support nor benefits. The state provided approximately 100 euros, but it was almost nothing since we spent 500 euros per month.'*

Parents experienced discrimination in an offered service of a children's camp – the child was not accepted because of the severity of their impairment. They further highlighted the duty of the state to offer various services to parents so that they need not look for support services themselves in such difficult and emotionally challenging circumstances:

*'They did not let the child participate in the town camp ... active programme and lots of moving around...'*

*'... impaired children should be offered various services instead of the parent forced to look for these...'*

**Supracategory 'Needs linked to the treatment process'** was formed of two subcategories: needs linked to medications and needs linked to worsening of the disease.

**Needs linked to medications** were demonstrated by the following examples:

*'When I acquire a digital prescription for the medicine, I need to start searching for the pharmacies that have this medicine in stock...'*

*'... I have searched and driven around town to find the medicine.'*

**Needs linked to worsening of the disease:** to acquire an individual and effective treatment plan for the child, persistent consultations with the physician were considered to be important:

*'... we are altering the treatment plan cooperatively with the physician...'*

*'The system should be more uniform so that everything that is necessary for the support in the case of this disease, for example an ophthalmologist and physiotherapy, are found in one system.'*

**Supracategory 'Needs linked to school requirements'** was formed of two subcategories: needs linked to assistance in studies and needs linked to communication with the school.

**Needs linked to assistance in studies:** one participant noted that teachers should accept obstacles and limitations caused by the impairments. A special teacher training about impaired children should also be available:

*'Teachers should accept that their manual activity and everything linked to joints has limitations ... all teachers need training on special needs.'*

Another participant highlighted the need for special assistant teachers and a personal approach to the learning process with additional explanations:

*'... needs personal approach and explanations.'*

**Needs linked to communication with the school:** one parent mentioned the need to communicate with the school; however, collaboration with every institution is not good. One school sent the father a message with an ultimatum written by a coordinator noting that the parent would plan the illness and absence of the child beforehand; after leaving that school for another the problem was solved. The new school has a specialist/social pedagogue providing assistance whenever needed:

*'... the coordinator dealing with special needs children asked if I was planning when my child would be ill?! ... and now there is a special social pedagogue at school providing lots of help to us.'*

#### 4. DISCUSSION

The experiences and needs of parents of children with JIA in coping with the child's disease were investigated in the current study. The lack of nursing papers in this field proves the topicality of the theme from the perspective of nursing practice.

The parents who participated in this research considered the beginning of the disease to be the most difficult period, and they had negative experiences in adapting to their child's illness. Many of the parents had experienced anxiety, fear and confusion associated with the unknown. Similarly, Bruns et al. (2008) and Anthony et al. (2011) have found in their studies that emotional experiences of parents of children with arthritis vary during the course of the disease, the dominant ones being a growing anxiety, fear and confusion. Asula (2014) has found that, in addition to quick reaction and appropriate disease-related problem-solving skills, parents should also have stress management skills.

The lack of sufficient help and support was also complained of in the present study. A specialist, family physician or paediatrician was mentioned as the main support in the healthcare system. However, it was noticed that teamwork and nurses were never mentioned in the role of a supporter. Laanemets (2013) has found that after confirmation of the JIA diagnosis, it is extremely essential for the parents to understand the nature of the disease and how it affects their child's health. The same is confirmed by Yuwen et al. (2017) in their study: the most complicated challenges for the parents regarding the disease were linked to the lack of information about the disease and its management.

Mawani et al. (2013) have published research showing that social support reduces stress in parents of children with JIA, and that social support programmes significantly reduce their mental health problems. Gheibizadeh et al. (2020) have found in their research that parents in a better economic situation cope more effectively with their child's disease. It was further demonstrated in the current research

that parents were waiting for the social system to help them. There was also a need for smooth access to healthcare services. It was requested that several specialist appointments could take place on the same day.

Yuwen et al. (2017) conducted a study, which showed that parents strongly expressed their wish to share their experiences with other families with the same diagnosis. Several authors such as Laanemets (2013) and Burbage et al. (2015) have also confirmed that if the parent is able to participate in support groups for parents of children with a chronic disease, it is of great benefit to them. The current research further proves the need for support mechanisms for parents. This need should be forwarded to the relevant organisations by the rheumatological multidisciplinary team.

McNeill (2004) reveals that one of the most difficult challenges for parents is the exacerbation of the disease and the pain experienced by the child. Parents found it important to have appropriate medications, noting that the welfare of the child is directly linked to the correct treatment plan and good communication between the family and the specialist.

Cassidy et al. (2010) write that typically the child's primary caregivers are the parents, who have several assignments to complete such as administering medications and injections, taking the child to the doctor's appointments, renewing prescriptions and buying medications. The subjects in this study highlighted the good relationship between parents and the importance of support from family and friends as the main source of psychological help. However, parents felt that more understanding from teachers was needed regarding the obstacles and limitations stemming from the child's disabilities.

## 5. CONCLUSIONS

The research demonstrated that parents' experiences in coping with the child's disease were linked to adaptation, feelings, nature of the disease, family relations and various support mechanisms. Parents went through negative emotions, especially at the beginning of the illness, related to uncertainty, such as fear and anxiety, about the unknown. Despite the lack of information, which hindered adaptation to the disease, parents were still able to cope with the situation and enjoyed good or even improved family relations.

Support for coping with the disease was received from both a specialist and a family physician. In order to get help from the local municipality, parents often had to ask for it themselves. However, when it came to obtaining assistive devices, they managed with their own resources.

Parents' needs in managing a child with the disease were linked to supporting the child's coping, the treatment

process and school requirements. In order to get a nanny service, parents would require state support. Regarding the treatment process, parents desired effective cooperation with healthcare workers during the exacerbation of the disease.

Parents felt that more understanding from teachers was needed regarding the obstacles and limitations stemming from the child's disabilities. Also, according to parents, special trainings would be valuable for teachers to engage with disabled children.

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## Juveniilse idiopaatilise artriidiga laste vanemate kogemused ja vajadused lapse haigusega toimetulekul

Mare Tupits ja Sirje Tarraste

Kõige levinum reumatoloogiline haigus lastel on juveniilne idiopaatiline artriit (JIA). Haiguse diagnoosimisel on vanemate valdav emotsioon kasvav ärevus, hirm, segadus ja haiguse eitamine. JIA-d põdevate laste vanemad ei saa Eestis piisavalt tuge ja teavet oma lapse terviseprobleemide või ka sotsiaaltoetuste ja -teenuste kohta.

Uurimistöö eesmärk on kirjeldada juveniilse idiopaatilise artriidiga laste vanemate kogemusi ja vajadusi lapse haigusega toimetulekul. Metoodika on kvalitatiivne ja kirjeldav. Andmete kogumiseks kasutati poolstruktureeritud intervjuu meetodit ning tulemusi analüüsiti induktiivse sisuanalüüsi abil. Intervjuud viidi läbi 2021. aastal ja uurimistöös osales kaheksa perekonda.

Uurimuse tulemusena leiti, et vanemate kogemused lapse haigusega toimetulekul sisaldasid tundmusi seoses haigusega kohanemisega, vanemate tunnetega, lapse olukorra arvestamisega, peresuhetega, haiguse olemusega ja erinevate toetustega. Haigusest teadasaamisel kogeti hirmu ja ärevust. Vanemate vajadused olid seotud lapse toimetuleku toetamisega, raviotsustega ja kooliga. Lapse toimetuleku toetamiseks soovisid vanemad saada psühholoogilist abi. Raviotsustega teemal soovisid vanemad teha senisest enam koostööd tervishoiutöötajatega haiguse ägenemise ajal. Vanemad vajasisid õpetajatelt rohkem mõistmist oma laste puudest tulenevate takistuste ja piirangute asjus.

Lapse haigusega kohanemisel kogesid vanemad nii positiivseid kui ka negatiivseid tundeid ning infopuudust. Pered peaksid tundma tervishoiutöötajate, kohaliku omavalitsuse ja õppeasutuste toetust.