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Research Article

The Experiences and Needs of Parents of Children with Diabetes in Coping with a Child`s Disease

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Abstract

Background and Purpose: The prevalence of diabetes among children and teens is increasing worldwide. Type I diabetes is one of the most common chronic diseases among children and can radically change the lives of children and their families. This study aimed to describe the experiences and needs of parents coping with a child's diabetes.

Design and Methods: Descriptive and qualitative research methods were used. The data were collected through semi-structured interviews and analysed by an inductive content analysis method. Interviews were conducted during the summer of 2021. Ten parents of children with diabetes participated in the research.

Results: The parents' experiences of coping with the child`s disease were related to living arrangements and family relationships, mental and physical health, knowledge, educators, and the support of specialists from various organisations. The parents` coping needs were mainly related to diabetes treatment and equipment, better support from relatives, health professionals and specialists, and improving society`s awareness. Based on the research results, more support and information could be provided to parents of children with diabetes. Considering the needs of parents, the provision of more effective and patient-centred nursing care is possible.

Practice Implications: Nursing care should support the coping of children and their caregivers, improving the lives of children and their relatives. The central focus for health care providers should be developing strategies for emotional support, reinforcement, and caregiver education.

Keywords: Child; Coping; Experience; Need; Type I Diabetes

What is Currently Known?: Type I diabetes is one of the most common chronic diseases among children that radically changes the life of children and their families. Parents would like to gain as much knowledge and skills on coping with the child´s disease as possible to maintain child´s optimal health and ensure their own life quality.

What does this Article Add?: The problem of attitudes and awareness among educators is a new theme, which has not been highlighted in prior research papers. Therefore, more attention should be paid on counselling and training the educators. It is also necessary to create a supportive group for the parents of children with diabetes to manage the disease of the child more effectively.

Introduction

In 2021, about 8.4 million individuals worldwide had type 1 diabetes; of these, 1.5 million (18%) were younger than 20 [1]. The results of a meta-analysis by Mobasseri [2] showed that the incidence of type 1 diabetes was 15 per 100,000 people, and the prevalence worldwide was 9.5%. The incidence and prevalence of type 1 diabetes are increasing [2]. By 2040, the number of cases is predicted to increase to 13.5–17.4 million [1].

Living with diabetes remains a challenge for children, as poor metabolic control may result in acute complications of hypoglycaemia or ketoacidosis, poor growth, and vascular complications [3]. Children and adolescents with diabetes are also at risk for depression and elevated distress [4]. A connection has been found between a child´s uneven blood sugar levels and conflicts in their family, as parents are more stressed. Worsened relations in the family lead to decreased coping with the child`s disease [5].

Caring for a child with diabetes impacts the mental health and well-being of children and their parents, causing more stress in parents with sensitive mental health. The general stress of the parents is increased by the depressive state of the child and an unwillingness to learn to manage their disease. Parental stress may significantly influence the relationship between child and parent. Children can sense when a parent is stressed, which can lead to a disruption in family life in the long term. However, a child willing to manage their disease could reduce the associated stress levels of the parents. [6]. Most stress is caused by the long-term effects of the disease on the child´s health and the possibility of complications [7]. Many parents take the responsibility to care for their child and follow the treatment plan because they do not trust others to be responsible for the process [8].

After the diagnosis has been confirmed, family members of the patient experience several complicated emotions, and numerous changes are introduced into their daily routine. Effectively dealing with emotions and following schedules are necessary to appropriately treat the disease and avoid secondary complications. Understanding the nature of the disease is important for the family and loved ones so that they can collaborate with the health care team and follow the treatment schedule [9]. However, parents confirmed that the attitudes of health care professionals should be more empathetic and understanding [10].

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Family-centred care provides a framework to take on the responsibility to care for children in ways that support and promote physical health and the healthy emotional and psychological development that occurs in the context of family [11]. Nurses have an important role in diabetes management in collaboration with the family. Nurses must use evidence-based knowledge to empower families with information and skills according to their individual needs [12].

The diagnosis of diabetes in a child presents a complex situation affecting the entire family. The onset of a paediatric illness significantly alters the life of the affected child and their immediate family. Parents want to acquire as much information and expertise as possible about managing their child´s illness to maintain the child's optimum health and ensure their own quality of life. [13]. The experiences of parents of children with diabetes have been previously researched [8, 14, 15] along with their needs [10, 13]; however current research broadens information and adds new perspectives to this topic. An enriched knowledge of parents´ needs and experiences in coping with the disease allows nurses to support families in various and empathetic ways.

Current research was conducted in the framework of larger research, The needs, experiences and coping strategies of parents with children that have a chronic disease. This larger applied research examined the experiences and needs of parents of children with cancer, asthma, diabetes, juvenile idiopathic arthritis, inflammatory bowel disease, and cerebral palsy in coping with their child's disease. The results of studies conducted with parents of children with cancer, asthma and juvenile idiopathic arthritis have been published [16-19], studies of parents' experiences with their childrens` inflammatory bowel disease and cerebral palsy are still ongoing.

This research aimed to describe the experiences and needs of the parents of children with diabetes in coping with the child`s disease.

Materials and Methods

Study Design: This research was qualitative and descriptive. Qualitative methods are used to understand people´s beliefs, experiences, attitudes, behaviour, and interactions [20]. A qualitative research method was chosen to describe the current topic because the collected data were based on pure experience, and this approach helps to understand the researched phenomenon more efficiently. Semi-structured interviews were used for data gathering, and the data were analysed using the inductive content analysis method described by Elo and Kyngäs [21].

Sample and Setting: The study leader from Tallinn Children's Hospital confirmed an initial agreement with the participants and forwarded participant contact information to the researchers. Prior consent from the participants was gained. After that, the researchers contacted potential participants by phone or e-mail. The Estonian Society for Pediatric and Adolescent Diabetes (ELDÜ) was contacted to find possible participants. Participants were informed of their rights. After reaching an agreement, the consent form, Participant information and consent form for the interviewee was sent to the participants by e-mail and signed before the interview.

Inclusion Criteria for the Research were as Follows: the parent of a child 2–18 who was at least one year beyond the initial diagnosis of type I diabetes; able to share information for research purposes; fluent in Estonian to avoid inaccuracy derived from language skills; and a consent form to participate in the study. Interviews were conducted remotely; therefore, the participant's location was unimportant.

Data Collection: Semi-structured interviews were used because they allow information about all fields linked to the research problems and follow-up questions while maintaining the individuality of the participant.

A plan for semi-structured interviews was written based on earlier research [22]. The interview plan consisted of introductory questions regarding the participant, child and family, followed by the experiences linked to coping with the child´s disease and the needs for managing their child´s disease. The conclusion allowed the participants to add anything or write something more specific if they wished to. Since the current research was conducted in the framework of larger research, a similar interview plan had been used previously, and conducting a pilot study was unnecessary.

The sample size was sufficient if additional interviews did not identify new topics, which is called data saturation [23]. The authors considered the database saturated after the tenth interview if topics started to repeat and there were no new themes. Interviews were conducted by nursing students, mentioned in the acknowledgements chapter, under the guidance of authors K.K. and M.T. One interview was conducted with each participant. The interviews were conducted individually, and the subjects had no contact with each other.

Interviews were planned to be conducted at meetings with the participants; however, the COVID-19 pandemic resulted in restrictions. Therefore, the interviews were conducted using various means of communication: four by video (using Zoom), four by phone, and two in writing. Thus, the interview questions were sent to two participants by e-mail with the possibility to contact the researchers to clarify the questions. Interviews were recorded in Zoom and on the phone using Windows Recording Studio. Data were transcribed as soon as possible after the interviews using Microsoft Word. A suitable date and time were agreed upon before the interviews. The researchers sent information and consent forms to the interviewees beforehand to sign digitally. Using different means of communication caused some differences in the results. In Zoom, one can observe emotions expressed through body language, but there is no such possibility in the written form. Using remote methods for interviewing allowed the researchers and participants to save time. The interview lengths varied: the shortest was 18 minutes, and the longest 60.

Data Analysis: When conducting qualitative research and analysing interviews, one can select between inductive and deductive content analysis strategies. Inductive content analysis is used if no research exists on the same phenomenon or the information is fragmented [21]. Since there was limited information about the subject, inductive content analysis was used in the current research for data analysis.

Data gathering and analysis are often parallel activities in qualitative research [24]. Data analysis was started immediately after conducting the first interview. Interviews were recorded and transcribed immediately after carrying out the interviews. Anonymity was ensured by coding the interviews by numbers (e.g., M1=the first interview conducted with the mother; F2=the second interview carried out with the father). The data analysis was carried out in collaboration with the nursing students mentioned in the acknowledgements chapter and the authors K.K. and M.T. The nursing students analysed the experiences and needs of mothers and fathers separately, and authors K.K. and M.T. combined the results of mothers and fathers into a whole.

According to Elo and Kyngäs [21], during the interview and while rereading the transcript, the main keywords or substantive codes should be written out so that no information collected during the interview will get lost. This stage is called open coding. The authors wrote the main ideas corresponding to the research problems and formed them into substantive codes. Substantive codes were transferred to coding pages and categorised by topics. Then, subcategories were formed. The next step was grouping subcategories into categories; lastly, the main categories were formed. Grouping continued until the result was reasonable and possible [21]. Two major themes were formed: parents´ experiences coping with their child´s disease and their needs in coping with their child´s disease.

Ethical Considerations: The current research was conducted in the framework of applied research, The needs, experiences and coping strategies of parents with children that have a chronic disease. Tallinn Health Care College gave permission to conduct the research (No 1-16/39, issued on 02.06.2020), and the Research Ethics Committee of the National Institute for Health Development issued approval (decision No 396, issued on 07.07.2020).

All study participants were asked to sign informed consent declaring an understanding of the aim and contents of the research and readiness to participate voluntarily. Participants were informed of the anonymity of the research and that they could withdraw consent at any time. To increase credibility, the interviews were conducted in similar conditions without any third parties present at a time suitable for the participants, avoiding differences from the environment or the interviewer. The authenticity of documented data was ensured by recording the interview, allowing it to be reproduced later. Anonymity was granted by using codes that could be linked to each participant only by the authors of this paper.

According to Elo and Kyngäs [21], authentic quotes may be used in research to increase the validity, demonstrating to readers which data categories were used to form current categories. By using quotes, no person or place names were used to keep their authors anonymous [21]. Data collected during the research were accessible to the authors of the research only. Sound files and computer data related to participants were deleted, and paper materials were destroyed at the end of the research.

Results

Socio-Demographic Data: Five mothers and five fathers participated in the study. The mean age of the subjects was 41. The youngest was 32, and the eldest was 46. Two mothers had university degrees (bachelor's or master's), one was acquiring hers, and two had a high school education. Three mothers worked full-time, one studied, and one was a housewife. Two fathers had university degrees (bachelor's or master's), one had a high school education with a vocational speciality, and two had a high school education. All five fathers were working full-time. The ages of the children with diabetes varied: the youngest was six, and the eldest had just turned 18. The latter was diagnosed at age 12.

Parents´ Experiences in Coping with the Child´s Disease: The main category, "Parents´ experiences in coping with the child´s disease", comprises substantive codes, which were united into five categories and 14 subcategories (Table 1).

Experiences Linked to the Living Situation and Family Relations: Parents received sufficient support from their spouses, other family members, and acquaintances. Some participants noted no change in close relationships compared to the time before receiving the diagnosis. Parents experienced that the family bonded together; however, sometimes irritation, worrying, and misunderstandings were noted. Most participants highlighted that family members became even closer and more cohesive after confirmation of the diagnosis.

Categories	Subcategories	Examples from quotations
Experiences linked to living situation and family relations	Experiences linked to support from loved ones Experiences linked to changes in living situation	*"...we have always been there for each other in the family, and we support one another." (F1)* *"Family life was changed a lot because diabetes is such a disease where routines are important in nutrition…" (M2)*
Experiences linked to parents´ health	Experiences linked to parents´ mental health Experiences linked to parents´ physical health	*"There was great sadness at first, and well, it is sometimes there now, too." (F5)* *"I have stomach problems, cannot say if this irritation was caused by the child´s disease or not." (M4)*
Experiences linked to knowledge	Experiences linked to lacking knowledge Experiences linked to knowledge of diabetes Experiences linked to child´s awareness of the disease	*"… it would be nice to get information just by calling somewhere if needed." (F4)* *"It was a serious problem at first to find carbohydrates and to calculate." (F5)* *"Child begins to have discipline in his or her routine himself…" (F4)*
Experiences linked to support from specialists of various organisations	Experiences linked to the Estonian Society for Paediatric and Adolescent Diabetes Experiences linked to insufficient support from instructors Experiences linked to experience counsellor´s and support person´s support Experiences linked to support from hospital staff members	*"We have received lots of knowledge, help and support from the Estonian Society for Paediatric and Adolescent Diabetes."(F2)* *"Instructor did not seem the most competent to me …" (M1)* *"… experience counsellor came from there, constantly advised us by phone." (M2)* *"Doctor and diabetes nurses were always available." (M5)*
Experiences linked to educators	Experiences linked to kindergarten staff Experiences linked to school staff Experiences linked to non-formal educators	*"It is important to me that they can go to kindergarten now and everyone next to the child would be aware of it." (M2)* *"...staff avoided the training that was desired to complete…" (F1)* *"… child was rejected from many camps…" (M1)*

Table 1: Parents´ experiences in coping with the child´s disease.

"Family simply offered moral support because they could not actually help anyhow, because no one had any experience with a child with diabetes." (M2)

Most participants experienced extensive changes in their daily and family lives. One of the mothers did not perceive the change as intensive because diabetes was not the child's first chronic disease. Another mother sensed that the elder child was paying less attention during adaptation to the disease than before. Based on their own experiences, parents claimed that after their child's diagnosis, situations arose in their lives that they needed to control. After receiving the diagnosis, the parents realised the necessity of better planning in their daily lives.

It changed a lot, just everything was turned upside down after the diagnosis. (sighed). From the beginning of the same hour…I had to quit my job officially when the child was diagnosed with diabetes I." (M2)

Experiences Linked to Parents´ Health: Regarding parents´ mental health, emotional instability and stress were emphasised. After confirmation of their child´s diagnosis, parents sometimes felt worried, irritated, or insecure. Parents also reported sadness caused by the diagnosis, especially in the beginning.

"Major stress and long-term (pause) I was quite nervous all the time. If a person is under pressure then they react immediately if someone uses for example louder voice…"(M3)

When describing their physical health, parents mostly reported fatigue and exhaustion. Sleep disturbances were described as having a negative impact on physical health.

"Most influential for the family was the blood sugar level check at night, which resulted in exhaustion."(F4)

Experiences Linked to Knowledge: Parents felt that they lacked the latest information and stable support. They experienced how important it was for information to be shared regularly and always available.

"Families research on the internet of new options but it would be nice to get information just by calling somewhere if needed." (F4)

The parents emphasised that they had to learn the specific nature of diabetes. Several participants highlighted that they had to learn a lot about administering the medications and how to perform procedures at first.

"We learnt various activities: how to administer, equipment... injections, cannulas, disinfection, drawing blood from fingers..." (M2)

Parents learned that discipline in a child´s life is vital after the diagnosis. They also sensed a need to control their child´s behaviour regarding nutrition. One of the participants revealed that their child is not ashamed of their disease and has self-confidence.

"I have to tell you, our child has never been ashamed of his disease." (M4)

Experiences Linked to Support from Specialists of Various Organisations: The Estonian Society for Paediatric and Adolescent Diabetes provided the parents with information about various events and counselled and supported parents and educators.

"Estonian Society for Paediatric and Adolescent Diabetes organised a training at school of the child for the teachers and a school nurse, which helped a lot and we have not had any specific problems at school." (F5)

Participants noted inadequate support and guidance from the instructor. Some participants had negative experiences regarding the training.

"Instructor did not seem the most competent to me... scared the kindergarten staff…" (M1)

An experienced counsellor and support person provided much help to the participants.

"Next day after our arrival from the hospital, then there was a lady that called us and really supported, and it was so unexpected, and it was really good… let´s say… right words at the right time." (M3)

Participants mentioned support from the hospital staff, including the doctor, endocrinologist, and diabetes nurse. Some participants said that support from hospital staff has always been available. At the same time, the parents mentioned that doctor´s appointments were unpleasant, service was unavailable, and doctors were undesirable.

"...they forced us the pump… we felt ourselves very uncomfortable and after that the spouse started to visit the endocrinologist." (M1)

Experiences Linked to Educators: When it comes to kindergarten staff, on the one hand, there was awareness in the kindergarten and, on the other hand, a negative attitude among kindergarten staff members. One of the participants highlighted that they could not get a place in the kindergarten for a long time because staff members lacked training on diabetes. Another participant mentioned that the child missed kindergarten for a year after the diagnosis, and kindergarten staff were worried that they could not cope with a child with special needs.

"Kindergarten staff had the attitude that we were not welcome there… We could not go there for a long time… we had to conduct a training in the kindergarten…" (M1)

Regarding school staff, teachers were aware of the disease yet afraid of whether they could cope with it. School staff lacked information about the disease; thus, parents think educators need counselling. It was essential for the participants that the educational institution had staff members aware of the child´s disease so they could monitor their health status and, if necessary, help the child.

"Firstly, schoolteachers had no experience... they were scared of situation where anything could happen to the child." (M1)

Regarding non-formal educators, it was noted that staff members feared managing the disease, children were rejected from camps, and awareness of children´s sports clubs was noted.

"We wanted to take up sports, but strangers denied observing this diabetes condition." (M3)

Parents' Needs in Coping with the Child's Disease: The main category, "Parents' needs in coping with the child´s disease", was formed of substantive codes categorised into 11 subcategories and four categories. (Table 2) explains parents´ needs in coping with the child´s disease.

Needs Linked to Diabetes Treatment and Equipment: All participants considered diabetes equipment availability and discounts important. Some participants wished for even more discounts or a variety of discounted products. According to the parents, the discount rate for diabetes equipment depends on the child´s age and decreases the older the child is. Regarding automatic insulin pumps, parents needed to learn how to use them, and they wished all families could afford automatic devices.

Categories	Subcategories	Examples from quotations
Needs linked to diabetes treatment and equipment	Needs linked to diabetes equipment Needs linked to diabetes treatment	*"...to introduce all automatic devices to be used for diabetes treatment…" (F4)* *"That child could perform his duties with as less stress as possible…" (F1)*
Needs linked to family and personal life	Need to decrease the workload of family members Need to cope with a child´s daily life	*"Reducing workload of the parents and close ones." (F4)* *"If a child is home alone then we have to remind them something" (F1)*
Needs linked to gaining support	Need for support from health care employees Need for social interaction Need for support from loved ones Need for information and counselling Need for support from a support person	*"It is needed to communicate with anyone continuously to get information…" (F4)* *"...lots of support from experiences of other parents of children with diabetes…"(F4)* *"Relatives could help more. We do not have that a lot." (M2)* *"Initial problem was that we had absolutely no idea of the disease, we had no information about it…" (M2)* *"Service of a support person for diabetics is very limited." (M3)*
Needs linked to society´s attitude	Awareness in the society Need for counselling in the community	*"...secretly giving injections in a lavatory… avoids other people´s glances." (M1)* *"...a child has diabetes and many people do not know what it actually means." (F2)*

Table 2: Parents´ needs in coping with the child´s disease.

"How about cannulas, sometimes a child takes them off on the first day, there are not enough of them for a year. And parents must pay for them. A box for a month costs 350 euros, which can be costly." (M3)

Financial difficulties should not impact the quality of diabetes treatment. Interviews revealed the need to not worry about the financial situation and the belief that the child´s treatment should not suffer from these consequences. Parents felt that there should be constant support without fighting to receive it.

"State should have stable regulations, so that we should not fight with Social Insurance Board about if any disabilities would be determined or not." (F5)

Needs Linked to Family and Personal Life: To reduce the family's workload, they must find trustworthy people so the parents have time for themselves. Parents consider it essential to have someone trustworthy and skilled with enough knowledge of diabetes to help the family so they can, for example, go on a short trip alone. Parents value counselling by a specialist to avoid overburden.

"Possibility to find a trustworthy person who has skills to perform necessary procedures so that we could go somewhere with the spouse for more than a couple of hours only." (F5)

According to the parents, the most important aspect of a child's daily existence is the child's ability to independently manage daily procedures and problems. Sometimes, it was necessary to exert control over the child so that he or she would develop the habit of self-observation.

"…that they could manage the problems independently… that they learn to feel when and how much to eat and what are the consequences." (M4)

Needs Linked to Gaining Support: When it comes to gaining support from health care professionals, parents revealed that it was vital that employees were there for them regularly and that the parents could continuously ask for information if necessary.

"…Children hospital´s support about equipment. Everything else is on your shoulders only." (F4)

Communication with other parents is important because they wish to share practical experiences and need networking. Currently, one of the parents has independently contacted another parent to share their experiences because a child´s classmate is suffering from the same disease. Interviews revealed the need for a network where they could share experiences and discuss the disease.

"I wish there would be a network in the future for parents of children with diabetes to share their life experiences with." (F1)

Parents mentioned the need for support from family, friends, and colleagues. Some parents wished for more time for themselves and wanted to rest more efficiently. One of the participants highlighted that if personal needs are satisfied, there is no need for additional support.

"...maybe time for myself. These are important details for the mum." (M3)

The parents considered information availability at the point of confirming the diagnosis extremely crucial. Interviews also revealed their need for more counselling.

"Everything was so sudden; at the moment we had no idea what the carbohydrate is. Everything, beginning with how to apply for their disability, what to begin with and all these rehabilitation plans…" (M4)

Parents wished the family had a support person to ask for help. Currently, the availability of support person services is limited.

"There is a need to get services, such as a support person, instead of a couple of hours a week but as much as needed, so that the parent could go to work properly..." (M2)

Needs Linked to Society´s Attitude: Participants mentioned classmates' fears, diabetic children feeling bad in social environments, and a lack of diabetes awareness. Parents were worried because there was not enough awareness of the disease, which may cause children to feel miserable when they are out of the home. Parents found it very important for people surrounding the child to have knowledge of the child´s disease and be ready to support the child if necessary.

"More understanding and attitude that the child is ill. Let me give you an example, we have to talk to the chef in the kindergarten about the menu today and what is it made of." (M2)

Parents highlighted that community counselling is needed because of fear and ignorance of the disease. Parents find it essential that the community is not afraid of diabetes; instead, they should complete the training offered and learn about the nature of the disease. Parents deemed it necessary to raise awareness in the community, noting a need to counsel other parents, for example, how to alleviate their workload and create well-being in the family.

“Kindergarten staff avoided the training that should be completed if there is a kid with diabetes in their group. Staff members should be aware of to avoid their fears.” (F1)

Discussion

The current research paper aimed to describe the experiences and needs of parents of children with type I diabetes in coping with their child`s disease. Considering the experiences and needs of the parents, it is possible to offer child- and family-centred nursing care. The Institute for Patient- and Family-Centered Care`s (IPFCC) definition of family-centred care includes four core concepts: respect and dignity, information sharing, participation, and collaboration [25]. In paediatrics, respect and dignity encompass how the child and family are treated [26]. Health care practitioners should honour patient and family values, beliefs, and choices and incorporate these into the delivery of care [25]. The findings from this research reveal that parents had both positive and negative experiences concerning health professionals` attitudes. The participants were mainly satisfied with the help they received from the endocrinologist and diabetes nurse. Yet one of the participants evaluated their contact with health care employees as unpleasant.

Information sharing is one of the core concepts of family-centred care. According to the IPFCC, information sharing involves communicating and making information available to patients and their families in formats they understand. Patients and families should receive timely and accurate information to effectively participate in care and decision-making [25, 26]. Research revealed that the parents received lots of information and responsibility after the child´s diagnosis had been confirmed. Participants reported that the knowledge gained from diabetes nurses about the child´s disease is enough; however, they still feel insecure. Salvador [27] noted the importance of nursing care because nurses can give the family information and teach skills to care for the ill child. The aim is to maintain the family´s quality of life and prevent complications from the disease. Parents who participated in this study described their greatest challenges as gaining information about the disease and learning to perform the procedures. Khandan [8] highlighted that mothers especially looked for additional information from various sources. Parents´ answers revealed that much information was gained from other mothers of children with the disease, chat groups on social media, and thematic summer camps. Most participants indicated that they found lots of information and support from the Estonian Society for Paediatric and Adolescent Diabetes.

Parents needed to learn to manage the daily lives of their children. They described emotional and physical fatigue derived from their child´s disease because the basis of diabetes treatment is regular monitoring of their blood sugar levels and calculating the necessary carbohydrates to be consumed, even at night. Kimbell [15] emphasised that measuring a child´s blood sugar level and calculating the necessary amount of carbohydrates is stressful for the parents. Similarly, as described by Čergelytė – Podgrušienė and Gudžinskienė [13], most participants interviewed by the authors of the current research experienced great changes in life after their child was diagnosed with the disease. It was also written by Jönsson [28] that diabetes causes changes in family life. Parents reported increased stress levels, lack of sleep, and exhaustion. Iversen [14] mentioned, likewise, that being a parent of a child with diabetes demands regular alertness, both physical and mental, to treat the child´s disease. Constant alertness and having no rest may result in total exhaustion over time. Continuous sleep deprivation and exhaustion may result in insufficient treatment routines for the child and cause conflicts in the family.

Participants perceived enough support from their loved ones. Relations in the family tended to become even closer after the diagnosis, or there was no change compared to the time before the confirmation. The participants highlighted that families stay together and support and encourage each other; however, sometimes irritability, worrying, and misunderstandings occur. Still, insecurity and fear occurred when other family members were responsible for following the treatment routines. Several parents had to quit their jobs or organise their work in a way considering their child’s needs so that they could check blood sugar levels during the day and take care of the child´s nutrition. The participants wished for more availability of a support person. They would like to find a support person available to help 24/7.

It is important for parents to share responsibility in coping with a child´s disease; however, some parents find it difficult to share responsibility in the family, such as determining who should help and to what extent. Similarly, Kimbell [15] and Iversen [14] reported that it was difficult for parents to hand responsibility for their child over to other family members and friends. Khandan [8] described that many mothers had taken the responsibility to care for their children and follow the treatment plan because they did not trust others to manage it correctly. Good relations in the family and support from loved ones are significant, helping parents to decrease their workload and allowing them to rest more. More support was requested from relatives because mothers needed more time for rest and self-care. Čergelytė – Podgrušienė and Gudžinskienė [13] emphasised that families need psychological support and various ways to spend their free time to cope with and alleviate their stress.

Participants of this research expressed worry about their child avoiding complications later in life due to their activity or inactivity. Aldubayee [7] highlighted that the greatest stress was caused by the long-term effects of the disease on the child´s health and possible complications. The parents also highlighted the difficulty in understanding that type I diabetes is a chronic disease that will follow a child until the end of their life. They wanted to find a cure for the disease, and it took some time to learn to live with and accept it. It seemed to the parents that the disease limited their child´s life. Diabetes nurses play a major role in explaining to the parents that type I diabetes cannot be eliminated, but it does not have to stop a child from living. A child can be active and participate in non-formal education like before the diagnosis. The intensity of diabetes nurses’ work on inclusion and supporting the parents is important.

Parents were concerned because of a lack of disease awareness among people surrounding their child, and, therefore, the child might experience negative emotions outside their home. Parents emphasised that they had to raise awareness in the kindergarten or school environment to educate the people spending daily time with their children and enlighten them on the truth and myths regarding the disease. It was crucial to the parents that people surrounding their child have more knowledge of diabetes and can help and support the child if necessary.

All the participants considered the availability of equipment, services, and discounts important. Parents wished for more discounts on equipment or a wider variety of discounted products. Parents worried about the discount system and possible changes and wished for more modern accessories. After the diagnosis, daily costs for the child increased. Jönsson [28] mentioned in their research that families’ daily costs for food and medications increased due to the child´s disease. Having discounts is also vital to help the families cope better financially, and the availability of support people would allow mothers to work full-time. Compared with other countries, Estonia has bottlenecks in the social benefits system. Parents of children with chronic diseases are often in more difficult financial situations, which itself worsens their ability to cope with the child´s disease.

From the aspect of child- and family-centered care, it is also important to consider participation and collaboration. Participation entails including the family in decision-making for the child’s care at the level they choose, while collaboration comprises partnering with families to improve policies and programs [25, 26]. Regarding participation, developing a child´s responsibility and skills to control the disease is important. A child should be included in the treatment routines as much as their abilities allow it. Sharing responsibility among family members teaches the child to gain skills step-by-step to manage the disease independently in the future.

The core of family-centred care is the relationship between families and health professionals, whereby families are considered full partners in providing health care to children. To provide family-centred care, health professionals must have an attitude and practice of respect, collaboration, and support [11].

Study Limitations: One limitation of the research was the small number of participants. Because it is a sensitive and difficult topic, not all invited parents wanted to participate in the study. Another limitation is that only Estonian-speaking parents were studied. Including parents who speak other languages would have made it possible to see different points of view and cultural differences. The fact that the results of this study overlap to a large extent with the results of previous research papers may also be a limitation. One major limitation was that face-to-face interviews could not be conducted due to the COVID-19 pandemic. Direct interviews would have made it possible to establish trust and notice the emotions and body language of the subjects. In qualitative research, another limitation is that the results cannot be extended to all parents whose children have a similar diagnosis. Nevertheless, the authors of the research hope that nurses and other health professionals will get ideas and advice to improve the support and counselling of parents of children with diabetes.

Conclusion

The experiences of parents coping with a child´s disease, namely diabetes, were linked to support from their loved ones and changes in their daily life, mental and physical health, support from various organisations, and knowledge and awareness of the disease. Parents expressed that their family became even more uniform after the child´s diagnosis; however, stress occurred in family relations, and it was difficult to share the responsibility of caring for the child. Several parents had to quit their jobs or reorganise their schedules to accommodate their child´s needs. Logistic changes had to be introduced in the family’s daily life, including conscious choices considering the child´s disease. Parents highlighted that the disease caused insecurity and sometimes fear in them. Parents described increased stress levels, insomnia, and exhaustion, which may lead to burnout. Acquiring information about the disease and learning to perform procedures was considered a major change. In general, the participants were pleased with help from the diabetes nurse and endocrinologist, and the information availability was considered good. Information was also obtained from parents of children with the same disease. Most participants agreed that they received much help and support from the Estonian Society for Paediatric and Adolescent Diabetes. Some difficulties occurred in kindergarten and school because educators feared they could not monitor the child´s health condition and had no idea how to help if necessary.

Parents´ needs in coping with the child´s disease were mainly linked to treatment of diabetes and equipment; reducing the family´s workload; more support from loved ones, health care employees, and other specialists; and the need to communicate with parents of children with the same diagnosis. Parents consider it necessary to raise awareness in society about diabetes. It is important that people surrounding the child have enough knowledge of diabetes and be ready to support and help the child if necessary. They also wished for more support from their relatives and found they needed more time to rest and be alone. All participants considered it essential to have excellent accessibility to services and equipment and to have discounts. They wanted more discounts on accessories or more variety of discounted products. They were concerned that the discount system could change in general or if their child was getting older. It was also noted that supportive people should be more available, allowing the parents to work full-time.

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Declaration of Conflicting Interests

The authors report no actual or potential conflicts of interests.

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How Might this Information Affect Nursing Practice?

A new theme occurred, namely the problem of attitudes and awareness among educators, which was never highlighted in prior research papers. Therefore, more attention should be paid to counselling and training educators. In terms of collaboration, creating a network for family members is necessary. A supportive group for the parents of children with diabetes would help to manage the child’s disease more effectively. Sharing their experiences regarding their child´s disease would support the parents’ mental health. In doing so, the feelings of isolation among parents of children with diabetes would be reduced significantly. There should be more focus on the mental health of parents of children with diabetes to support their coping with the child´s disease and avoid burnout. Based on the experiences and needs of the parents and considering the research results, it is possible to offer more effective and patient-centred nursing care.

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