

FAMILIES' EXPERIENCES OF DIABETES GUIDANCE IN PEDIATRIC WARD 1

Sanni Räsänen
Markku Niemelä

Bachelor's Thesis
December 2012

Degree Programme in Nursing
Social services, health and sport



DESCRIPTION

Author(s) NIEMELÄ, Markku RÄSÄNEN, Sanni	Type of publication Bachelor's Thesis	Date 12.12.2012
	Pages 43	Language English
		Permission for web publication (x)
Title Families' experiences of diabetes guidance in pediatric ward 1		
Degree Programme Degree Programme in Nursing		
Tutor(s) SINIVUO, Riikka; PUNNA, Mari		
Assigned by Central Finland central hospital, pediatric ward 1		
<p>Abstract</p> <p>Diabetes is one of the fastest spreading diseases in Finland and worldwide. The prevalence of type 1 diabetes has quadrupled during the past 50 years. It is not known why Finnish children get diabetes more than others, as is yet unknown what has caused the increase in the prevalence of the disease.</p> <p>The purpose of the thesis was to find out and describe the lived experiences of diabetes guidance in ward 1 among families with a child diagnosed with type 1 diabetes, as well as to find out how families' individual needs are taken into account in the diabetes guidance. The research was carried out in cooperation with the pediatric ward 1 and the pediatric polyclinic at Central Finland central hospital.</p> <p>The method used for data collection was questionnaire with open-ended questions. Collected data which consisted of three responses was analyzed using thematic content analysis.</p> <p>The results of the study show that families had good experiences of the period they spent in pediatric ward 1. Diabetes guidance in the ward is well planned and customized for each family. Further research is, however, recommended to be done on the same subject with a longer data collection period, since the collected data for this thesis turned out to be rather brief.</p>		
Keywords Type 1 diabetes, family, experience, guidance		
Miscellaneous		

Tekijä(t) NIEMELÄ, Markku RÄSÄNEN, Sanni	Julkaisun laji Opinnäytetyö	Päivämäärä 12.12.2012
	Sivumäärä 43	Julkaisun kieli Englanti
		Verkkojulkaisulupa myönnetty (X)
Työn nimi Families' experiences of diabetes guidance in pediatric ward 1		
Koulutusohjelma Degree Programme in Nursing		
Työn ohjaaja(t) SINIVUO, Riikka, PUNNA, Mari		
Toimeksiantaja(t) Keski-Suomen keskussairaala, lastenosasto 1		
<p>Tiivistelmä</p> <p>Diabetes on yksi maailman nopeimmin leviävistä sairauksista Suomessa ja maailmanlaajuisesti. 1 tyypin diabeteksen esiintyvyys on nelinkertaistunut viimeisen viidenkymmenen vuoden aikana. Ei tiedetä, miksi suomalaiset lapset sairastuvat diabetekseen useammin kuin toiset. Ei myöskään tiedetä, miksi taudin esiintyvyys on kasvanut.</p> <p>Työn tarkoituksena oli selvittää ja kuvata perheiden kokemuksia diabeteshoidonohjauksesta lastenosasto 1:llä perheissä, joissa on 1 tyypin diabetekseen sairastunut lapsi. Tarkoituksena oli myös selvittää, kuinka perheiden yksilölliset tarpeet huomioidaan diabeteshoidonohjauksessa. Tutkimus toteutettiin yhteistyössä Keski-Suomen keskussairaalan lastenosasto 1:n ja lastentautien poliklinikan kanssa.</p> <p>Aineistonkeruussa käytettiin avoimista kysymyksistä koostuvaa kyselylomaketta. Aineiston analysointimenetelmänä käytettiin teemoittelevaa sisällönanalyysiä. Aineistonkeruu tuotti kolme vastausta.</p> <p>Tutkimuksen tulokset osoittavat, että perheille jäi hyvät kokemukset sairaalajaksolta lastenosasto 1:llä. Diabeteshoidonohjaus osastolla on laadittu hyvin ja se on yksilöity jokaiselle perheelle sopivaksi. Lisätutkimusta suositellaan kuitenkin tehtäväksi samasta aiheesta pidemmällä tiedonkeruujalla, sillä tähän tutkimukseen kerätty aineisto osoittautui suppeaksi.</p>		
Avainsanat (asiasanat)		
Tyypin 1 diabetes, perhe, kokemus, ohjaus		
Muut tiedot		

CONTENTS

1	INTRODUCTION.....	2
2	TYPE 1 DIABETES AS A DISEASE.....	4
3	DIABETES GUIDANCE.....	10
4	FAMILY-ORIENTED APPROACH IN DIABETES GUIDANCE.....	13
4.1	The child’s developmental tasks and guidance	14
5	DIABETES EDUCATION IN WARD 1.....	18
6	PURPOSE, AIM AND RESEARCH QUESTIONS	20
6.1	Purpose and aim of the study.....	20
6.2	Research questions.....	21
7	STUDY DESIGN AND METHODS	21
7.1	Participants.....	22
7.2	Data collection.....	23
7.3	Data analysis.....	23
8	RESULTS OF THE RESEARCH.....	25
9	DISCUSSION.....	28
10	ETHICAL CONSIDERATIONS AND RELIABILITY	29
11	CONCLUSIONS	32
12	REFERENCES.....	34

APPENDICES

Appendix 1 – Cover letter	38
Appendix 2 – Questionnaire	39
Appendix 3 – Coding sample.....	40
Appendix 4 – Research permit	41

TABLES

Table 1: Diabetes guidance work distribution in Ward 1.....	18
---	----

1 INTRODUCTION

Diabetes is one of the fastest spreading diseases in Finland and also world-wide. Over 500 000 Finns have it and it takes 15% of the resources in the health care sector. (Groop, Antikainen, Isomaa, Laakso, Laine, Lindström, Nikkanen, Puurunen, Saltevo, Syväne, Toivonen & Tulokas 2007.) The risk of getting type 1 diabetes is the highest in the world amongst Finnish children (Vaarala 2004; Mustajoki 2011). The prevalence of type 1 diabetes has quadrupled during the past 50 years. It is not known why Finnish children get diabetes more than others, as is yet unknown what has caused the increase in the prevalence of the disease. (Keskinen 2011, 332.) In this study we focused on families with a child diagnosed with type 1 diabetes, because it is the most common type of diabetes among Finnish children. (Op.cit.)

Nowadays children are involved more and more in their own treatment. They are often independent and they want - and also need – to know a lot about the treatment of their disease. Therefore the way they get the first information about the disease is crucial. The child needs guidance to learn how to deal with the changes that the disease and its treatment cause to the child's condition and daily life. Good guidance may reduce child's fears towards the hospital, too. Giving the child information helps him to understand the meaning of the situation and to participate in decision making regarding his own health. This lessens the child's fear. (Salmela 2011, 33-34.)

As it is stated in one of National Advisory Board on Health Care Ethics' publication; "*Children shall be treated equally and as individuals, and they shall be allowed to influence any decisions concerning them in accordance with their individual stages of development.*" (Shared values in health care - common goals and principles 2001.) Even though parents' role is important, the child has to be taken into account in nursing as he is an autonomous and unique individual. It is important to note the child's evaluations and expectations about the quality of care during the hospitalization because the main focus of

the care is on the child. (Pelander 2008, 13.) This is why we wanted to study the families' experiences, not only the parents', and hoped that also the voices of the children could be heard from the answers.

The need for the thesis came from the ward in question after the authors had discussed with the diabetes nurses in this unit. The purpose of the study was to describe the lived experiences of diabetes guidance in ward 1 among families with a child diagnosed with type 1 diabetes. The aim of the study was to find out how the families experience the diabetes guidance given in the ward and how the families' individual needs are taken into account in the diabetes guidance. One goal was also finding out how to improve the diabetes guidance to meet the families' needs better if need for such action seems current. The results of this study can be used in developing the diabetes guidance given to the families in the ward.

It has been shown in several studies that patients who are more satisfied with their care are more likely to participate in their care and follow advice and directions. Individualized nursing care has been shown to lead into patient satisfaction and health-related quality of life. (Pelander 2008, 21.) Therefore, in order to make sure that the patient – in this case the child with diabetes, along with his family – does the self-care as well as possible, the guidance and treatment should meet his wishes whenever possible.

This bachelor's thesis was done in cooperation with the pediatric ward 1 in the Central Finland central hospital.

2 TYPE 1 DIABETES AS A DISEASE

Physiology

Diabetes is a disturbance in energy producing metabolism, which is essential to life. Elevated blood glucose level is the indicator for diabetes. It is due to lack of the hormone insulin, the malfunction of it or both. Disturbances in fat and protein metabolism are often related to diabetes. (Saraheimo 2011, 9.) Type 1 diabetes is an autoimmune disease. It means that for some, mostly for unknown reasons, the body attacks against the insulin producing beta cells in pancreas destroying those little by little which, in turn, leads to insulin deficiency. (Hämäläinen, Kalavainen, Kaprio, Komulainen, Simonen 2008, 17.)

The pancreas is a large vascular gland located in the back of the abdominal cavity. Its main purpose is to produce various hormones needed in metabolism. It stores, manufactures and releases the hormone called insulin, which adjusts glucose levels in blood. More specifically, beta cells of the pancreas are the ones producing insulin. In addition to blood glucose regulation, insulin also facilitates the transport of blood glucose into the cells all over the body. It is also needed in producing adipose tissue, proteins and glycogen, which is the form of storage sugar in liver and muscles. Insulin also stimulates the hunger and satiety centers in the hypothalamus of the brain. (Fain 2009, 466.)

Without insulin the body cannot utilize all the food and therefore doesn't get enough energy. Insulin transports the glucose from blood to tissues. In healthy body the pancreas senses all the changes in the blood sugar and quickly secretes the necessary amount of insulin. During a meal insulin is secreted in large amounts, during fasting a little. This way the blood sugar levels stay in a good level (3-7 mmol/l). If there isn't enough insulin in the blood, the blood sugar level rises and the glucose is secreted to urine. This causes larger amounts of urine and also feeling of thirst. Because the body can't utilize the glucose, it starts to burn adipose tissue for energy. This way ketoacids are

built up to the body. Ketoacidosis is a life threatening situation, but when it is treated right, it doesn't leave marks to the body. Therefore it isn't relevant to the child's future at which stage the disease is diagnosed. (Hämäläinen et al. 2008, 18-19.)

Childhood diabetes begins with typical symptoms such as increased urination and thirst along with fatigue and bad appetite. The symptoms may begin during an infection when the child with flu may seem unusually tired. Wetting the bed may occur with small children. Symptoms usually develop over a period of a couple of weeks. The sooner those are recognized and responded to, the better. (Jalanko 2010.)

Type 1 diabetes does not develop overnight; instead, it takes months or years. When it is diagnosed there are 10-15% left of the beta cells. Little by little all cells are destroyed. (Hämäläinen et al. 2008, 21.) The rate of beta cell destruction varies but it is generally faster in children than adults. When the individual suffers from insulin deficiency he cannot survive without administering insulin daily into his body. (Fain 2009, 467.)

It is not yet known why one's body starts to destroy beta cells, but apparently diabetes develops, due to different factors, on a person who has a genetic vulnerability to get the disease. Some external factors which may trigger type 1 diabetes include various infectious diseases, nutrition during infancy, and lifestyle. (Hämäläinen et al. 2008, 19; Fain 2009, 467.)

Guidelines and aims of the treatment

As stated in Käypä hoito recommendations (Groop et al. 2007) the common goals of diabetes care and treatment include prevention of diabetes related complications and ensuring good quality of life free from symptoms. Keeping the blood glucose level as normal as possible is essential. Too low blood glucose levels need to be avoided, as well as unnecessary limitations (Ilanne-

Parikka 2011, 254). Goals are always determined per individual, together with the patient. Some typical goals may be generated for almost every single patient but the starting point is to have them tailored to each one's individual needs. Goals are recommended to be recorded in patient records and clear, numeric goals should be set. (Groop et al. 2007.)

Care and treatment guidance aims to improve quality of life and to prevent acute complications and associated illnesses. It should be noted that the primary responsibility of treatment is on the diabetic himself and his family. Health care professionals are there to help and guide but they cannot supervise patients on a day-to-day basis. It is crucial that the patient is familiar with the disease and actively participates in the care. In order for treatment to be successful the diabetic needs to have adequate information, skills, and will to care for himself. A well guided patient has better chances on finding ways to control the illness which, in turn, improves the quality of life and treatment results. (Groop et al. 2007; Komulainen, Lounamaa, Sipilä & Knip 2004.) As mentioned in Pettoello-Mantovani, Campanozzi, Maiuri and Giardino's (2009) work *"Each child and family's innate strengths should be respected and the health care experience must be considered as an opportunity to build on these strengths and support families in their care-giving and decision-making roles"*. They also mention the importance of involving children in their own care from an early age.

As said before, Käypä hoito -recommendations state that the primary responsibility of treatment is on the patient and his family, but diabetes nurses and doctors are the ones primarily responsible for diabetes guidance. In addition to these two it is also recommended to have multi-professional co-operation with e.g. podiatrists, dietitians, social workers, and psychologists or psychiatrists, as they can provide assistance in many important matters and help in dealing with the changes thrown by the newly diagnosed chronic disease. (Silverstein, Klingensmith, Copeland, Plotnic, Kaufman, Laffel, Deeb, Grey, Anderson, Holzmeister & Clark 2005; Komulainen et al. 2004.) Diabetes guidance is at best patient-oriented, planned, and continuous (Groop et al. 2007).

When arranging and implementing guidance and choosing the content the team needs to bear in mind that work distribution between those involved in care guidance needs to be clearly planned. It would be ideal if these parties met regularly to discuss common goals, ensure everyone's on the same page and stay united on methods and ways of carrying out the guidance. All professionals need to be up-to-date on their skills and knowledge. (Groop et al. 2007; Silverstein et al. 2004.) This is backed up by Howe, Ayala, Dumser, Buzby & Murphy (2010, 122-124) who studied parental expectations in the care of children with diabetes. Parents expect to get expert advice from providers and, furthermore, expect them to be competent, knowledgeable and up-to-date.

The guidance aims to provide the child and his family with the knowledge and skills to enable them to make decisions regarding self-care and diabetes treatment. Important factors in all this are right timing (grasp the things that are acute), continuity (proceed one step at a time), and planning. Upon recent diagnosis guidance focuses on the necessary basic information and skills. Even after self-management has started and everyone has absorbed the basics of diabetes care the guidance still goes on. It is a life-long process. (Groop et al. 2007; Silverstein et al. 2005.)

The methods of diabetes treatment

In the beginning of treatment when diabetes is diagnosed, the child's condition needs to be stabilized by administering adequate amounts of insulin to get the elevated blood glucose level down. If the child suffers from ketoacidosis, he needs to be hydrated either intravenously or per orally. Later on, when the situation is stabilized, the diabetes guidance is started immediately in the ward to the whole family. (Saha 2011, 335.)

The treatment consists of adjusting the right amount of insulin in each situation. Required amounts are individualized and they change along with aging. Also the duration of the disease affects the amounts administered. (Keskinen 2011, 339.) Measuring the blood glucose level is an essential part of the treatment from the very beginning. At first it must be done densely. That way the influence of insulin, the eaten carbohydrates and exercise can be seen. Later on when the body's functions are better known, measuring can be done less frequently. (Saha 2011, 349.) A dietitian is often needed when planning the child's meals together with the family. Calculating carbohydrates, eating healthy snacks, having regular meal times and trying to keep a normal body weight belong to a diabetic's life. (Kalavainen 2011, 351-353.) In order to stay healthy, doing sports is important to everyone and especially to children. Sports support the treatment of diabetes. Self-monitoring helps in treating diabetes right also when doing sports. (Saha 2011, 358.)

Previous research

According to Olli (2008) the information gotten from nurses lessened the fear for diabetes. On the other hand, parents had said that the information they got felt like an onslaught. They had thought about their own and the child's capability to receive the amount of the information right after the diagnosis. In parents' opinion, the surprise of getting ill and all the emotions going on had weakened the readiness of receiving the information. Parents taking part in the research felt, however, that the education given in the ward was well planned and comprehensive, and they had felt as if they had been studying or in a training while they were in the hospital. (p. 102). The most permanent care relationship had developed between the family and the diabetes nurse, because it had been the same nurse all the time and there had been no hurry going through things. (Op. cit.).

Children's Hospital Boston has an experience journal where they show quotes from patients and parents of those who have been cared for in their facility.

Reactions vary from mild shock to almost complete denial. Most parents find the role and support of nurses and doctors as the most important factor in coping with the illness. However, even among them there are variations as to what kinds of things they think should be talked about during the initial phase. Youngsters and teenagers, while appreciative of the care, find that the staff doesn't necessarily know how to communicate with them and often they feel like they are treated either as small children who do not have a mind of their own, or as adults. (Children's Hospital Boston). Schmidt, Bernaix, Chiapetta, Carroll & Beland (2012, 91) found that most parents experienced diagnosis as emotionally disturbing. Words, such as "overwhelming" and "heartbreaking" were used. Some parents found it to be sad and depressing, and some experienced feelings of guilt, as if it was their fault that the child fell ill.

For her thesis Hörnsten (2004) researched experiences of diabetes care from patients' and nurses' perspectives, although her focus was on type 2 diabetes. The study was carried out in Umeå, a mid-sized town in northern Sweden. Results of her research are quite much the same as most other studies we have read for our own thesis. It should not come as a surprise that often patients' and health care professionals' (HCP) viewpoints on diseases are different. Patients worry about the impact of the disease on their everyday life, whereas HCPs focus more on effects on their wellbeing. (pp. 19-20). Results of the same study also point out satisfaction on clinical encounters where HCPs show sensitivity and understanding, lend an ear to really listen to what patients want and feel, and see them as persons with strengths and weaknesses instead of merely patients and/or medical diagnoses. (pp. 35-36).

3 DIABETES GUIDANCE

General principles for guidance

The starting point for high-quality guidance is patient-oriented approach. It is based on respecting the patient's dignity and caring for him as a person. It enables mutual respect and tendency to deal with the issues so that a common understanding is reached. Patients differ from one another in several ways, therefore also their needs and styles for learning are different, and this provides a challenge for guidance. (Kyngäs 2008, 27.)

High-quality guidance is defined as being tied to the context of the instructor and the one receiving the guidance. It is active and goal-directed activity, where the instructor and the one receiving the guidance are interacting. The main elements of the guidance are the context of the instructor and the one receiving the guidance, interaction, the guiding relationship, and active and goal-directed activity. Professional responsibility of the nursing staff and proper resources are also part of this. When done properly high-quality guidance is effective: it has been found to support managing with the disease, promotes quality of life and commitment to treatment, and adds feeling of safety and satisfaction towards treatment. It also lessens anxiety and fears, promotes self-care at home and lessens the usage of health care services. (Op.cit.)

Special features of diabetes guidance for children and adolescents

A child's fast growing, development and dependence of the close environment give special features, which need to be considered in diabetes treatment. When choosing the form of treatment, the family's daily life needs to be noticed. The treatment of diabetes needs to be bound so closely to the family's daily rhythm that the child and the family can continue to live as normal life as possible. Still, a good balance in the treatment has to be kept. (Ruusu & Vesanto 2008, 126-127.) Frustration occurs when prescribed diabetes regi-

mens are not tailored to the unique demands of the family's lifestyle and therefore don't fit into the family's daily life (Howe et al. 2010, 124).

The child's treatment and the guidance for the family are arranged following the principles of nurse and doctor-in-charge. It is planned group working. The whole family takes part in the diabetes guidance and, if necessary, also grandparents and other people responsible for the child's care (e.g. people from day care or school). The guidance is given paying attention to the child's age and developmental level. The guidance is individualized and continuous and it proceeds step by step. The family's needs and life situation are to be taken into account. In the guidance for a newly diagnosed child, at first during the shock phase only the information needed immediately is given to the family, such as in injecting insulin, doing the self monitoring, preventing and acting in hypoglycemias, and following a diet. (Ruusu, Vesanto 2008, 126-127)

The book *Diabeetikon hoidonohjaus* (Kotisaari, Kuisma, Kyngäs, Lahtela, Olli, Pekkonen, Peränen, Poskiparta, Reini, Rintala, Ruuskanen, Ruusu, Simonen, Turku, Vesanto, Winell & Österberg 2008) describes various factors that need to be considered when planning and implementing education and guidance interventions. At first, the factors behind the patient and the context where he lives in the daily life need to be identified. These factors are physical, psychological and social, which all include many details.

Physical factors affecting diabetes guidance

These factors affect how the person is able to take in the guidance. Things like age, sex, educational background, and the health belong to this group. (Kyngäs 2008, 30-31.)

In the case of children and adolescents, especially age is a major factor affecting the planning and implementation of guidance. When guiding a child with diabetes there usually are one or several family members with him. Everyone

taking part in the guidance has their own factors which all affect the situation as well. If the child understands what is discussed in the guidance he must not be left as an outsider, as these experiences have an effect on how the child finds the guidance later on in life when he grows up. (Op. cit.) When thinking about the self-care of a child one has to remember, in addition to family members, the other people around the child's daily life, for example the staff in school or in day care. (Katz, Laffel, Perrin & Kuhlthau 2011, 861.)

Guiding an adolescent can be a special challenge if the person doesn't want his parents to attend the guidance sessions. In these cases the best result is reached if it is possible to discuss and find a solution together with the young. However, diabetic adolescents and their parents can be guided separately if doing it together turns out to be too challenging. (Op. cit.)

Psychological and social factors in diabetes guidance

Psychological factors include motivation, beliefs related to health, experiences, expectations and learning styles, and capabilities. The key element is motivation because that has an effect on whether the patient wants to embrace the issues related to his treatment, does he find those issues important to him, and how enthusiastically the nurse goes into the factors behind the patient and builds the relationship. Among all the other issues, finding a learning style that matches the child's developmental level and suits the whole family is very important. (Kyngäs 2008, 33-35.)

Social and cultural factors need to be considered in the guidance as well. In order to understand the patient's premises for guidance, the patient needs to be viewed in his living environment. The environment has an influence on how the patient learns self-care and how he implements it. To some people family means the world, to others something else is more important. It is known that a person with a long term disease needs the support from the close ones. In the guidance one must clarify whether the patient has people who can support

him in his life. (Kyngäs 2008, 35-37.) Although involving one's family is usually a choice originating from the patient, when talking about pediatrics the dynamics change, as children are dependent on their families or guardians (Pettoello-Mantovani, Campanozzi, Maiuri & Giardino 2009).

Some cultural factors can prevent the patient from fully taking part in the guidance. For example, if the patient's mother tongue is different from that of the nurse, it can cause feelings of anxiety, insecurity, and fear of misunderstanding important issues related to the treatment. (Kyngäs 2008, 36.)

4 FAMILY-ORIENTED APPROACH IN DIABETES GUIDANCE

Everyone defines family in their own way: family may consist of e.g. one child or several children and both parents or only one parent. Grandparents can also belong very closely to the child's life. In this study the focus will be on the unit child/children and parents.

In pediatrics the ground principle lies in the assumption that a child's primary source of strength and support is his family. Additionally, in clinical decision making family's perspectives and information are of great importance, as they are the experts of their everyday life. (Pettoello-Mantovani et al. 2009.) When a child is diagnosed with a long-term disease, it is always a shock to the family: it affects the whole family and relationships between family members (Ruusu & Vesanto 2008, 129-130; Hallström & Elander 2007, 196). There can be many practical problems related to the treatment, and getting ill may raise strong feelings. Life can easily end up revolving around the disease. It's important to keep in contact with the outside world and notice also other family members in addition to the sick child. (Ruusu & Vesanto 2008, 129-130.) When a child falls ill especially mothers tend to focus on the ill one while other siblings and spouse may be set aside (Hallström & Elander 2007, 196). However, parents should not forget taking care of each other, either (Ruusu & Vesanto 2008, 129-130).

Responsibility of the self-care at home needs to be shared and both parents should take part whenever possible. Also, siblings of the sick child should be involved in the guidance. That way also they get information about the disease and have a chance to discuss their thoughts and feelings. (Ruusu & Vesanto 2008, 129-130.) During the initiation of guidance a meeting with a psychologist is arranged to give the family emotional support. Usually the family also meets a social worker who gives the family information about social security of the sick child. The family is also informed about the local diabetes association's activities for families. The family and the diabetes team work closely together. In the beginning the treatment unit has responsibility of the treatment. Little by little as the family gains more skills and information, the responsibility is handed over to the family. The family needs to know which place to contact in case of problems or emergencies. (Ruusu & Vesanto 2008, 130-131.)

4.1 The child's developmental tasks and guidance

A developmental task means an issue which belongs to the normal development and which a person needs to go through before moving on to the next developmental level. In the guidance it is essential to pay attention to child's developmental level and implement the guidance with that in mind. One goal in the diabetes treatment is that the child feels healthy. It includes avoiding difficult hypoglycemia and ketoacidosis. It is important that child can play, go to school, have hobbies and do the things he likes despite diabetes. A successful treatment guarantees that the child grows and develops normally. Another goal is to prevent the long term organ alterations related to diabetes. Therefore the diabetic's blood glucose levels should be as near to normal as possible. Sometimes one has to be flexible with this so that the treatment doesn't get too heavy for the child and that the risk of getting difficult hyperglycemia wouldn't rise too much. (Ruusu & Vesanto 2008, 131.)

0-2-year-old

During the first two years many things happen in the child's life. He learns to walk and talk, and forms a basic body image. The crucial thing is the interaction between the child and an adult. Through this interaction the child develops the feeling of basic trust, which is the basis for the feeling of identity. The child learns to deal with feelings of being away from the adult.

The disease has an effect on developing body functions and learning of new things slows down. The changes in the care and in physical surroundings, as well as being apart from close ones unsettle the child's feeling of safety.

(Ruusu & Vesanto 2008, 132.)

3-6-year-old toddler

A toddler studies the environment and himself; he experiences that his actions are meaningful. Because the language, thinking and motor functions develop more and more, also self-confidence develops. When the child understands rules and norms it enhances the development of conscience. A disease creates a threat which is directed to the body image. (Ruusu & Vesanto 2008, 132.)

When the child is under school age, guidance and education is mainly given to his parents but the child can take part in his treatment if interested. Feeling of security is created by explaining why certain things must be done. It is useful to use games in guidance in difficult and scary situations. When playing, the child expresses his thoughts about the surrounding world. It is the best way of learning which also supports the child diversely. The one taking care of a small child has to be determined and logical in his actions: certain things must be done despite the child's protests and afterwards one has to show tenderness. The child needs to be given options to choose from when possible (for example does he want an apple or an orange). This way he gets the feeling that he can decide on something. (Op. cit.).

7-12-year-old

In this period of life the child's development is very much affected by parenting and own learning. The child has the need and ability to create. It is meaningful to the child to get an experience of own capability. The feedback from the environment has a big significance, as well as the feeling of frustration and disappointment.

The disease may, at this age, cause loneliness and difficulties in coping among friends. It may also cause limitations, which can lead to negativity against the treatment – the child may, for example, not eat a snack during school hours because others don't either. At this age the child can already understand consequences and the reason for the treatment. The child also thinks about the future. (Ruusu & Vesanto 2008, 133.)

At this stage guidance is already given more directly to the child and not to parents only. The child is able to practice and perform technical things like injecting insulin, taking blood and urine samples, and calculating the carbohydrates under supervision. Parents still have the main responsibility of the treatment but the child is given certain tasks to take care of, for example taking the insulin for dinner under supervision. During guidance sessions questions, such as what is diabetes and how it is treated, are answered.

A school aged child is encouraged to tell about the disease at school. This way friends don't have to wonder about the special things done during school and they understand why things are done the way they are. (Op. cit.)

12-18 -year-old adolescent

This is the time of life when the young person searches for himself. The young person needs to accept the physical development and reach the emotional independence from parents and other people. Conflicts with parents are normal. (Ruusu, Vesanto 2008, 134; Faulkner 2003, 362.) Many teenagers feel

controlled by authority figures and find frequent inquiries into their self-care and private lives displeasing (Davidson, Penney, Muller & Grey 2004, 73).

Self-perception may change in time because of the disease and self image may become focused on the disease. The young person may feel shame and guilt because of getting ill and feel that he is different from others. He may also be afraid of losing friends. (Ruusu & Vesanto 2008, 134.) Some teenagers consider being different from others positive as they feel having matured faster than others of same age (Huus & Enskär 2007, 30). Challenges brought on by the illness surpass the typical transitional experiences of youth for these teenagers as they enter adulthood (Faulkner 2003, 362). Diabetes sets certain restrictions and living regular life is often seen troublesome which can, however, be alleviated through finding coping strategies (Huus & Enskär 2007, 29-31).

The aim of the guidance of an adolescent is on mastering injections, taking blood and urine samples and practicing adjusting treatment regimen according to current situation. During guidance sessions the knowledge is deepened by answering the question "Why?". The support from parents and the diabetes group is important. Based on individual needs the adolescent may take additional guidance visits to go through practical situations. In the guidance things like foot care, associated diseases, smoking, alcohol, birth control, getting pregnant, choosing a career, driving license, travelling, social support and rehabilitation need to be gone through. Peer support can be very useful to the young person, too. (Ruusu & Vesanto 2008, 134-135.) In order to get teenagers to comply with care regimens they need to feel that compliance and its aims are achievable and meaningful within their lifestyle. Another affecting factor to compliance is the quality of relationships that a teenager has with friends, family and health care professionals. They also need to feel that their opinions are taken into account and they have more input into their care regimens. (Davidson et al. 2004, 73-77.)

The ideal end result of the guidance is a young person, who takes responsibility for his own health and who feels happy about his life. The role of the nurse is being a source of information and one who walks next to the adolescent on his journey. (Ruusu & Vesanto 2008, 134-135.)

5 DIABETES EDUCATION IN WARD 1

Pediatric ward 1 at Central Finland Central hospital has a clear structure for the care guidance and education to be given to each new diabetic and their family. The process is divided into four stages, spread through a duration of four days. This process and contents of each stage are described in the table below. Roles and tasks of each professional involved in the care are pointed out.

Table 1: Diabetes guidance work distribution in Ward 1

1) Admission Doctor/Diabetic nurse	<ul style="list-style-type: none"> - What is diabetes: basic knowledge, main principles of treatment - Feelings and emotions arising from having fallen ill - Scheduling the initial guidance
2) Day 1 Diabetes nurse	<ul style="list-style-type: none"> - Injecting insulin: - Equipment (insulin pen/syringe) - Injection technique - Practicing injections - Implementing insulin therapy - Types of insulin, duration of action - Principles of insulin dosage - Storage of insulin - Obtaining supplies
Dietitian	<ul style="list-style-type: none"> - Family's nutritional anamnesis

3) Day 2	
Diabetes nurse	<ul style="list-style-type: none"> - Implementation of self-monitoring at home - Frequency and techniques for measuring blood glucose and how to use the equipment - Interpreting results, values for target level - Marking down results in the notebook - Hyperglycemia - Hypoglycemia
Dietitian	<ul style="list-style-type: none"> - Principles of diet in treatment - Personal diet plan
Psychologist	<ul style="list-style-type: none"> - Meeting the family
Social worker	<ul style="list-style-type: none"> - Social security - Social services
4) Day 3	
Diabetes nurse	<ul style="list-style-type: none"> - Treatment of hypoglycemia and diabetic shock - Sick days - Physical exercise and blood glucose - Finnish Diabetes Association - Planning of continuing care, contact details
Dietitian	<ul style="list-style-type: none"> - Mealtime simulation

Diabetes nurses in ward 1 are responsible for the initial care and guidance to be given to new patients and their families. This task consists of holistic care, guidance and support in a crisis situation. In addition to support given in the ward they also offer counseling over the telephone. They are also responsible for recurring follow-up care periods for those who have had diabetes for some time already. These periods often consists of supporting the child or adolescent in self-care. Patients who come to the ward because of conditions like hypoglycemia and diabetic ketoacidosis are taken care of by diabetic nurses. In addition to being intensively involved in the care and guidance for patients and their families, diabetes nurses also educate other members of the staff,

and work as a part of a multi-professional work group. Ward 1 aims to offer timely service for families which is why diabetes nurses work in shifts. Although diabetes nurses provide the specialist care, every nurse working in the ward participates in the basic care of patients admitted to the ward. (Central Finland central hospital: Pediatric ward 1 diabetes guidance materials.)

As it can clearly be seen from the table above, the ward follows domestic and international recommendations in providing care and guidance for newly diagnosed diabetics and their families. A multi-professional team is involved in care, thus offering the family a wide picture and addressing various issues related to diabetes. The amount of information to be taken in during such a short period of time seems rather much. One of the indirect aims of this study is to find out whether it is too exhaustive for families or is it considered to be reasonably easy to have it sink in in only a few days' time.

6 PURPOSE, AIM AND RESEARCH QUESTIONS

6.1 Purpose and aim of the study

The purpose of this study was to describe the lived experiences of diabetes guidance in ward 1 in Central Finland Central hospital among families with a child diagnosed with type 1 diabetes.

The aim of the study was to find out how the families experience the diabetes guidance given in the ward and how the families' unique and individual needs are taken into account in the diabetes guidance. One aim was also to provide the ward with information on how to improve the diabetes guidance to meet the families' needs better, based on the results.

This type of survey had not been done in the ward before so it was first of a kind and will offer valuable information to those involved in care. It is important

for nurses to know how families find the guidance they get in the ward. Thus, they can develop their working methods to meet the families' needs better.

6.2 Research questions

- How do families experience the diabetes guidance given in the ward?
- How are families' individual needs taken into account in the guidance?

7 STUDY DESIGN AND METHODS

This type of study, in our opinion, required a qualitative approach. Qualitative research, unlike quantitative, uses words instead of numbers or statistics, and focuses on a profound understanding, description and interpretation of a phenomenon (Kananen 2008, 24). The goal is to understand perspectives of participants and to describe their lived experiences (Op. cit.; Kylmä & Juvakka 2007, 31).

Kananen (2010, 41) states that a study made of a phenomenon that is not known in advance requires qualitative research. He also adds that grounding a theory about the phenomenon can be done, but is not necessary. Qualitative research is said to be "hypothesis-free" and thus, no presumption should be set. (Kananen 2008, 28.)

Usually there are few participants in a qualitative study, sometimes only one. The reason for this is that the purpose is to collect as rich material as possible from the phenomenon being studied. The quality of the phenomenon is what matters, not the quantity. (Kylmä & Juvakka 2007, 27.)

Qualitative survey in form of questionnaire with open ended questions was the method of choice for data collection. Because of open-ended questions participants had a chance to explain their views and opinions in more detail and it allowed them to freely describe their experience within the limits of questions and each family's unique interpretation of those. A standardized questionnaire was used which means that each respondent answered same questions. Questions were constructed the way that those would be easy to understand.

Questionnaire was chosen because of practicalities. It is easy for participants to take home and fill it out taking their time. They are not tied to any specific time other than deadline for returning the questionnaire, unlike e.g. in interviews. Participants' anonymity was more protected as they did not meet with the authors in person – therefore a respondent cannot be connected to any answer. Although somewhat more restricting than interview, as it is not possible to pose any additional and clarifying questions, being able to answer anonymously is likely to encourage respondents to not inhibit themselves from speaking their mind.

7.1 Participants

For the study a purposeful sampling was used. Families were recruited from the pediatric ward 1 in Central Finland Central Hospital, as well as the outpatient clinic (polyclinic) where follow-up visits take place. Both units were aware of the study and agreed to hand out questionnaires to prospective participants.

The criteria for participation was as follows: (1) families have a child who has diabetes (2) care and guidance after diagnosis was received in pediatric ward 1 in Central Finland Central Hospital and (3) diagnosis dates back six months at most.

The amount of participants was unknown throughout data collection as it was difficult to predict how many new cases would turn up within the time period of

collecting data or how many follow-up appointments would take place, and how many of those families might decide to participate in this study. Due to a short period of data collection we were wishing to get five to ten responses for analysis. The final amount turned out to be three.

7.2 Data collection

Data collection took place during weeks 44-46 in October-November 2012.

In newly diagnosed cases the diabetes nurse gave the family a questionnaire upon discharge which they could fill out at home and then return it to the pediatric polyclinic. For those families where diagnosis had been received earlier and who come for a follow-up appointment at the polyclinic a questionnaire was offered there. They had an option to either fill it out while waiting or take it home and return it by the deadline.

7.3 Data analysis

Data was originally planned to be analyzed using inductive content analysis. In content analysis categories describing the content emerge from the data (Kylmä & Juvakka 2007, 112; Dawson 2009, 122). Content analysis aims to describe the raw data in compact and general form using words (Kananen 2008, 94). It is vital to recognize content-related statements that describe the phenomenon that is being studied. In inductive analysis the purpose and research questions of the study are the driving forces. All data is not necessary to analyze but answers to the purpose of the study and research questions are sought. (Kylmä & Juvakka 2007, 112-113.) This, however, was adjusted later and thematic analysis was combined to content analysis. Thematic content analysis, according to Anderson (2007, 1), is "a descriptive presentation of qualitative data". Common themes are identified in the texts that are to be analyzed.

To begin with data familiarization was required. All transcripts were read through by us both because one could have noticed something the other one fails to recognize. As the reading process went on returning to previously read transcripts was necessary if and when information that was not previously noticed emerged. Reading started with no preset categories or themes but those were rather sought from the data.

After having read through each response it was time to code data. This was done with the help of a word processor. All responses were first transcribed and then similar data highlighted using different colors. These chunks of colored text were then transferred to a new document and organized in sections by color. Once that was done each section was given a name that described the highlighted content. At this stage there were seven sections, each already a theme of their own. Names for themes came easily based on questions used in the questionnaire and research questions. Although this had not been the plan, as the process was started from a clean table without preset settings, the data allowed for that to happen. Some data fit into several themes which resulted in redefining and combining of those that could go together. After reviewing each theme several times, as an end result three main themes were formed.

The collected data consisted of three responses. All the answers were written into the space after each question. This wasn't the authors' purpose as there was a blank paper for the answers attached to each survey. It should have been mentioned in the cover letter since it is likely that the participants failed to realize that the small space after each question was not meant to limit the length of an answer. Thus, the answers for each question were short; only a few sentences. One of the respondents had used one sentence or only few words in answering each question. It was clear that to this respondent the illness is still new and a shocking thing. The other participants had more to say to each question. One of the respondents had clearly given more thought to

the survey as the answers were longer and the content was more variant and diverse.

8 RESULTS OF THE RESEARCH

As the analysis process started it was noticed that most data fell into categories that could be derived from questions used in our questionnaire that was given to participants, and furthermore could also be combined to our research questions. Although participants were not asked about the duration since the diagnosis was received the language used in responses gives a hint about whether it was a brand new thing, or if there had been time to process things for a while. There was a clear distinction between the usage of present and past tense. The authors' interpretation was that those to whom it was still a new thing tended to use present tense more than those, who had had time to adjust. Length of responses varied greatly as well.

Personal experiences and feelings

Participants felt that the information they received was relevant and there was no information overload. The quality of care and guidance was generally considered to be good and competent, even exceeding expectations. In fact, it was considered so good that one respondent did not wish for any changes to be made to how guidance is implemented in the ward.

“Care and guidance was very diverse, I did not even realize to expect that.”

“The care was really good and guidance was competent.”

One participant also expressed worry over maybe being a burden to the nursing staff, as well as a notion of the current nursing staff shortage problems. The former, however, may well be only authors' own interpretation, as there was no further explanation to this particular statement.

“At times it felt like there were too few nurses, when we had to constantly make them run around the ward.”

A subcategory **Views on the future** was derived from the main theme. Faith in coping with the new life situation having a child with diabetes was expressed, as was general satisfaction with guidance giving a good feeling that in the future everything will work out. This goes to prove that nursing personnel and other professionals involved in the care and guidance can have a significant effect on how families see their chances on coping with the disease.

“It’s such a new thing... We got positive feelings that we will make it.”

“I got really good feelings also about the future.”

Support and interaction with personnel

Participants felt that both verbal and non-verbal communication with the personnel worked very well and that interaction was straightforward and easy. They also stated that they had a feeling of being able to talk about everything possible with the nursing personnel. Nothing but praise was given on the support families received in the ward. Almost all professionals, from doctors to cleaning personnel, working on - or in cooperation with - the ward were mentioned, stating that each helped them one way or the other.

“We were received very well in the ward and the whole family was taken care of really well.”

“Support was received all the time... Nurses were warmhearted and helpful.”

Families' individual needs

All participants said their family's needs were acknowledged both through nursing interventions, as well as through making sure they were doing alright. Individual needs may mean different things to different people and this could be seen in responses. To one it could be e.g. taking into account their everyday life and choosing methods that best fit their lifestyle, whereas to another it could be a simple thing like making sure they are feeling comfortable and doing fine while in hospital.

“Our needs were paid attention to well. Medication that would be easy to administer to my child was chosen together.”

“They kept on asking how the family was doing and help was offered in adequate amounts.”

Having a private room for the family was seen as a positive thing and it was also mentioned under individual family needs.

“We had our own room almost the whole time.”

Input from multi-professional team was seen helpful in family's coping and being able to call the ward whenever needed adds to the feeling of security. It was also mentioned how easy dealing with day care issues was with the help of ward personnel.

“I got to meet, for example, a dietitian, psychologist, doctors, nurses, cleaning staff and social worker who each in their part helped us.”

9 DISCUSSION

Guidance is generally seen as an active interaction between the person giving the guidance and the one receiving the guidance. (Kettunen, Karhila & Poskiparta 2002, 213-222) The guidance given in the ward worked well in this light, since the participants all felt that the interaction was easy and their family as a whole was taken care of very well. They also got the feeling that they can talk about any matter they wished to.

It requires psychological knowhow and persistent strengths from the health care staff to support people with a long-term disease to adapt the new life situation and to help to accept the difficult stages of the treatment. The health care providers need to face sometimes difficult emotions and support the patient and their family through difficult times (Diabeetikon hyvän hoidon toteuttamisen periaatteet 2008, 5). According to the answers we analyzed, the nurses had succeeded in creating a hopeful and supporting atmosphere despite the family's shock of having a child with a long-term disease. No one expressed any wishes for changes to how care and guidance is carried out in the ward. This is, obviously, a great sign which shows the high quality of nursing practice in providing families with best of the best.

As it is already stated before, a multi-professional approach in diabetes guidance is highly recommended. (Silverstein et al. 2005; Komulainen et al. 2004.) It also comes out from the results that it is seen as a good thing to have a chance to meet people who each are specialists in their own field. This way not only the disease is treated and paid attention to, but also all other aspects of daily living and coping with changes are taken care of.

In pediatric ward 1 the initial diabetes guidance is carried out in small pieces during several days. This, apparently, is a well-working approach since the participants did not feel that they got too much information at a time and that the quality of the guidance was high. The participants also appreciated the way they were treated in the ward; they were constantly asked how everything was going and help was offered at any time. When it comes to improving the guidance given in the ward, the results do not offer any suggestions. However, the standard obviously is very high as it is and, therefore, it can be suggested to keep the current practices in use until or if further studies are done. They could also develop a short survey to collect information on a regular basis on their own.

10 ETHICAL CONSIDERATIONS AND RELIABILITY

In order to carry out a study like this a research permit needed to be applied. In our case it was applied from the Central Finland hospital district.

As baselines for ethics in health care research it must be noticed that research must not harm participants. Benefits of the study need to outweigh the possible harm. It is essential that participation is voluntary and participants can opt out at any time. (Vehviläinen-Julkunen 2006, 27.) Participant information must remain secret and confidential (Shared values in health care, common goals and principles 2001). Laws in Finland control health science research along with ethical guidelines (Kylmä & Juvakka 2007, 139).

The survey was done anonymously so that the participants did not need to write down their personal information anywhere. The questionnaire was returned to the polyclinic which is not physically connected to the pediatric ward 1. We did not meet the families and therefore couldn't have a direct effect on their answers or opinions. In the cover letter every family was informed

that filling out the survey is not mandatory and they are free to opt out at any given time, as well as about the fact that the results may and will be used in our final report. They were also informed that collected data will not be given to outsiders and all data will be destroyed when the analysis and final report are completed. Written informed consent was not obtained as such, as by deciding to participate they gave their consent.

Our contact information, along with that of our mentors, was written down in the cover letter. The same letter also clearly stated which institution we are studying in, the topic of our thesis, as well as information on the purpose of the study.

Reliability

Theoretical information was searched using academic databases, such as PubMed, SagePub, Ebsco, Duodecim, as well as magazine articles, books, the Internet, and any other relevant sources. Key words related to the study were used, paying attention to sources. One can find a lot of information but filtering out what is reliable and what is not is required, in order to get as accurate information as possible. Any material to be used we tried to narrate to publications published in the 21st century, preferably within past 10 years. The information also had to be relevant to the topic. Key words used in most searches were: Type 1 diabetes, family, experience and guidance.

As stated before, a purposeful sampling was used in order to receive answers from families who met the criteria and had personal experience of the topic studied. Questions asked in the questionnaire were revised several times in order to avoid them being too narrow or too wide. A challenge posed by a questionnaire lies in inability to ask further questions, as well as the missed non-verbal information, such as changes in the tone of voice, sighs, laughs and breaks (Nieminen 2006, 218). One has to be mindful that respondents may also not recall things as they happened if the timeframe is too broad, and

things that have happened in between may have altered their view of the occasion. Even when respondents are free to express themselves freely they may leave out relevant information, alter the truth, or say things they consider socially acceptable and think the researcher wants to hear. However, we need to trust that the information shared is accurate and true. For analysis purposes the data needs to be sufficient enough to enable conclusion-making, as researcher is not allowed to make the kinds of conclusions that cannot clearly be derived from the data. (Op. cit., 219).

It is in the nature of qualitative research that there is no single one interpretative truth, as researchers bring their own preferences and experience to the project, thus making the analysis a very personal process (Nieminen 2006, 215-219; Dawson 2009, 114). To decrease the possibility of researcher bias both authors read through every response in case the other one either e.g. missed something important or leaved something out as irrelevant. In addition to that the process was documented and justifications provided. To support the analysis direct quotations have been used to bring out the data as said by respondents.

Although the survey was kept as short as possible the authors acknowledged a danger that families, at that point, would not necessarily have the desire to do such a thing. The shock and adjusting to a new type of lifestyle may draw their attention to other things. In order to have them respond at least in brief, diabetes nurses were given instructions to inform families that their responses are highly valued and they are free to provide either long and extensive answers, or summaries. Details regarding the questionnaire were also provided in the cover letter. The goal was to have them give something we could work on.

Response rate was 100% as each participant to whom the questionnaire was given also responded. What we noticed upon the end of data collection when picking up questionnaires from the ward was the shortness of answers. Several factors could explain it, including willingness to keep things simple and

short, or even failure to realize that the responses were not limited to the questionnaire form, but those could have been continued on the blank paper attached to the questionnaire.

In an ideal situation there would have been a pre-testing period where the questionnaire would have been handed out to a selected number of participants and based on their responses changes could have been made. Afterwards a wider audience would have been involved and data collected during a longer period of time in order to get more extensive material base. Though in qualitative research it is not about the amount of data but the quality of it, having a few more responses would not have hurt. What was seen in the data was that it was not always written from the whole family's perspective, but from that of the person filling out the questionnaire. Had there been a pre-testing period upon realizing that we could have altered the questionnaire and the cover letter to emphasize the importance of everyone's input even more. We were hoping to hear the children's voices but those did not come up very strongly. However, every bit of data that was collected was and is valuable.

Since the number of responses was three, the research is not that extensive as it only tells opinions of three families of the diabetes guidance in the ward. The answers were also quite brief and there was not much of discussion about the asked themes. Even so, responses were all very similar in the way that, in their opinion, all things considered the diabetes guidance works well in the ward. This in itself is a good indicator as to what the state of diabetes guidance is like in the ward.

11 CONCLUSIONS

Based on the data it can be said that participants are happy with how the pediatric ward 1 is operated and how they, as health service users and clients,

are taken care of there. The participants did not have anything negative to say about the diabetes guidance.

As stated earlier the voice of the children did not come up as we had hoped for. The data collected for this thesis also produced only brief and limited material about the issue. In this light further research in this same area is recommended to get more reliable and richer data. More details on how and what kinds of alterations might need to be made were discussed at the end of chapter Ethical considerations and reliability.

During the data analysis it became clear that those participants who had had more time to process the illness and all the things concerning it gave more diverse answers and had given more thought to answering the survey. One could also sense from the answers that they had gotten some kind of peace with the whole matter and perhaps already accepted the new way of life with a child with a long-term illness. Therefore it is recommended that the further study would be carried out amongst those who have received diabetes guidance a bit longer time ago, for example from three to eight months ago. That way it might be possible to collect richer and more descriptive data even if using the same method as for this thesis, although the wider the time-frame, the more challenges it produces reliability-wise.

12 REFERENCES

Anderson, R. 2007. Thematic content analysis (TCA). Descriptive presentation of qualitative data. Accessed on 29 November 2012.

<http://www.wellknowingconsulting.org/publications/pdfs/ThematicContentAnalysis.pdf>.

Children's Hospital Boston. Experience Journal: Diabetes. Accessed on 20 April 2012. <http://experiencejournal.childrenshospital.org/?cat=21>.

Davidson, M., Penney, E.D., Muller, B. & Grey, M. 2004. Stressors and Self-Care Challenges Faced by Adolescents Living With Type 1 Diabetes. Applied Nursing Research. May 2004 17, 2. pp. 72 - 80. Accessed on 5 September 2012. <http://www.jamk.fi/kirjasto>, Nelli Portal, Elsevier.

Dawson, C. 2009. Introduction to Research Methods. How To Books:Oxford, United Kingdom.

Diabeetikon hyvän hoidon toteuttamisen periaatteet - Suuntaviivoja nuorten ja aikuisten tyypin 1 diabeetikoiden hoitoon ja kuntoutukseen. 2008. Suomen Diabetesliitto ry. Accessed on 5 September 2012. <http://www.diabetes.fi>.

Diabetes in childhood and adolescence. 2011. A global guideline from International diabetes federation. Accessed on 8 April 2012.

[http://www.idf.org/sites/default/files/Diabetes in Childhood and Adolescence Guidelines_0.pdf](http://www.idf.org/sites/default/files/Diabetes%20in%20Childhood%20and%20Adolescence%20Guidelines_0.pdf).

Fain, J. A. 2009. Understanding diabetes mellitus and kidney disease. The Nephrology Nursing Journal September-October 2009, 36, 5 Accessed on 6 September 2012

<http://web.ebscohost.com/ehost/pdfviewer/pdfviewer?sid=997ef3de-2446-461d-8880-d24c45d462de%40sessionmgr14&vid=7&hid=7>.

Faulkner, M. 2003. Quality of Life for Adolescents with Type 1 Diabetes: Parental and Youth Perspective. Pediatric Nursing. September-October 2003 29, 5. 362 - 368. Accessed on 5 September 2012. <http://www.jamk.fi/kirjasto>, Nelli Portal, CINAHL.

Groop, L., Antikainen, A., Isomaa, B., Laakso, M., Laine, M., Lindström, J., Nikkanen P., Puurunen, M., Saltevo, J., Syväne M., Toivonen, J. & Tulokas, S. 2007. Diabetes. Käypä hoito. Suomalaisen Lääkäriseuran Duodecimin, Suomen Sisätautien yhdistyksen ja Diabetesliiton Lääkärineuvoston asettama työryhmä. Reviewed on 30 November 2011. Accessed on 31 March 2012.

<http://www.kaypahoito.fi/web/kh/suosituksset/naytaartikkeli/tunnus/hoi50056?akusana=diabetes>.

Hallström, I. & Elander, G. 2007. Families' needs when a child is long-term ill: A literature review with reference to nursing research. *International Journal of Nursing Practice* 2007, 13. 193 - 200. Accessed on 5 September 2012. [Http://www.jamk.fi/kirjasto](http://www.jamk.fi/kirjasto), Nelli Portal, CINAHL.

Howe, C. J., Ayala, J., Dumser, S., Buzby, M. & Murphy, K. 2010. Parental Expectations in the Care of Their Children and Adolescents With Diabetes. *Journal of Pediatric Nursing*. 27. 119 - 126. Accessed on 5 September 2012. [Http://www.jamk.fi/kirjasto](http://www.jamk.fi/kirjasto), Nelli Portal, Elsevier.

Huus, K. & Enskär, K. 2007. Adolescents' experience of living with diabetes. *Pediatric Nursing*. April 2007 19, 3. 29 - 31. Accessed on 5 September 2012. [Http://www.jamk.fi/kirjasto](http://www.jamk.fi/kirjasto), Nelli Portal, CINAHL.

Hämäläinen, M., Kalavainen, M., Kaprio, E., Komulainen, J., Simonen, R. 2008. *Lapsen diabetes*. Jyväskylä:Gummerus.

Hörnsten, Å. 2004. Experiences of Diabetes Care – Patients' and Nurses' Perspectives. Umeå University Medical Dissertations; New Series No 882. Accessed on 25 July 2012. [Http://umu.diva-portal.org/smash/get/diva2:142838/FULLTEXT01](http://umu.diva-portal.org/smash/get/diva2:142838/FULLTEXT01).

Ilanne-Parikka, P. 2011. Tyypin 1 diabeetikon insuliinihoidon onnistumisen edellytykset. An article in the book *Diabetes*. Ed. Ilanne-Parikka, P., Rönne-
maa, T., Saha, M-T., Sane, T. Hämeenlinna: Kariston kirjapaino Oy.

Jalanko, H. 2010. *Diabetes lapsella*. Lääkärikirja Duodecim. Accessed on 26 September 2012. [Http://www.terveyskirjasto.fi/terveyskirjasto/tk.koti?p_artikkeli=dlk00114](http://www.terveyskirjasto.fi/terveyskirjasto/tk.koti?p_artikkeli=dlk00114).

Kananen, J. 2008. *Kvali – Kvalitatiivisen tutkimuksen teoria ja käytänteet*. Jyväskylä:Jyväskylän ammattikorkeakoulun julkaisuja.

Kananen, J. 2010. *Opinnäytetyön kirjoittamisen käytännön opas*. Jyväskylä: Jyväskylän ammattikorkeakoulun julkaisuja.

Katz, M. L., Laffel, L. M., Perrin, J. M. & Kuhlthau, K. 2011. Impact of Type 1 Diabetes Mellitus on the Family is Reduced with the Medical Home, Care Coordination, and Family-Centered Care. *The Journal of Pediatrics*. 160, 5. 861 - 867. Accessed on 5 September 2012. [Http://www.jamk.fi/kirjasto](http://www.jamk.fi/kirjasto), Nelli Portal, Elsevier.

Keskinen, P. 2011. Diabetes on yleinen sairaus lapsilla ja nuorilla. An article in the book *Diabetes*. Ed. Ilanne-Parikka, P., Rönne-
maa, T., Saha, M-T., Sane, T. Hämeenlinna: Kariston kirjapaino Oy.

Keski-Suomen keskussairaala: Pediatric ward 1 diabetes guidance materials. N.d.

Kettunen T., Karhila P., Poskiparta M. 2002. Voimavarakeskeinen neuvontakeskustelu. *Hoitotiede* 14, 5, 213 – 222.

Komulainen, J., Lounamaa, R., Sipilä, I. & Knip, M. 2004. Lasten ja nuorten diabeteksen hyvän hoidon laatuksikriteerit. *Lääketieteen Aikakauskirja Duodecim*. Lasten ja nuorten diabetes. 120, 8, 1135-7. Accessed on 25 April 2012. <http://www.terveyskirjasto.fi/xmedia/duo/duo94267.pdf>.

Kylmä, J., Juvakka, T. 2007. Laadullinen terveystutkimus. Helsinki:Edita.

Kyngäs, H. 2008. Hoidonohjauksen lähtökohtia. An article in the book *Diabeetikon hoidonohjaus*. Ed. Rintala, T-M., Kotisaari, S., Olli, S., Simonen, R. Keuruu: Tammi.

Mustajoki, P. 2011. Diabetes (sokeritauti). *Lääkärikirja Duodecim*. Accessed on 26 September 2012
http://www.terveyskirjasto.fi/terveyskirjasto/tk.koti?p_artikkeli=dlk00011.

Olli, S. 2008. Diabetes elämäkumppanina. An academic doctoral thesis from the University of Tampere. Tampere:Tampereen Yliopistopaino Oy. Accessed on 31 March 2012. <http://acta.uta.fi/pdf/978-951-44-7363-0.pdf>.

Pelander, T. 2008. The quality of paediatric nursing care-children's perspective. An academic doctoral thesis from the University of Turku. Turku: Painosalama Oy. Accessed on 1 September 2012
<https://www.doria.fi/bitstream/handle/10024/42602/Annales%20D%20829%20Pelander%20Diss.pdf?sequence=1>.

Pettoello-Mantovani, M., Campanozzi, A., Maiuri, L. & Giardino, I. 2009. Family-oriented and family-centered care in pediatrics. *Italian Journal of Pediatrics* 35, 12. Accessed on 5 September 2012.
<http://www.ijponline.net/content/35/1/12>.

Ruus, P. & Vesanto, M. 2008. Diabetesta sairastavien lasten ja nuorten hoidonohjaus. An article in the book *Diabeetikon hoidonohjaus*. Ed. Rintala, T-M., Kotisaari, S., Olli, S., Simonen, R. Keuruu: Tammi.

Salmela, M. 2011. Diabetekseen sairastuneen lapsen sairaalaan liittyvät pelot ja niistä selviytyminen. *Diabetes ja lääkäri*. September 2011, 40, 4, 33 - 34. Accessed on 3 April 2012.
http://www.diabetes.fi/files/1683/DjaL_4_2011_netti.pdf.

Saraheimo, M. 2011. Mitä diabetes on?. An article in the book *Diabetes*. Ed. Ilanne-Parikka, P., Rönnemaa, T., Saha, M-T., Sane, T. Hämeenlinna: Kariston kirjapaino Oy.

Schmidt, C. A., Bernaix, L. W., Chiappetta, M., Carroll, E. & Beland, A. 2012. In-Hospital Survival Skills Training for Type 1 Diabetes: Perceptions of Children and Parents. *The American Journal of Maternal/Child Nursing*.

March/April 2012 17, 2. 88 - 94. Accessed on 5 September 2012. [Http://www.jamk.fi/kirjasto](http://www.jamk.fi/kirjasto), Nelli Portal, CINAHL.

Shared values in health care, common goals and principles. 2001. A publication of ETENE (National Advisory Board on Health Care Ethics). Accessed on 10 September 2012.

[Http://www.etene.fi/c/document_library/get_file?folderId=18388&name=DLFE-675.pdf](http://www.etene.fi/c/document_library/get_file?folderId=18388&name=DLFE-675.pdf).

Silverstein, J., Klingensmith, G., Copeland, K., Plotnic, L., Kaufman, F., Laffel, L., Deeb, L., Grey, M., Anderson, B., Holzmeister, L.A. & Clark, N. 2005. Care of Children and Adolescents With Type 1 Diabetes. A statement of the American Diabetes Association. *Diabetes Care* 28, 1, 186 - 212.

[Http://care.diabetesjournals.org/content/28/1/186.long](http://care.diabetesjournals.org/content/28/1/186.long).

Vaarala, O. 2004. Tyypin 1 diabetes - suomalaisten lasten kansantauti. (Type 1 diabetes - the national disease of Finnish children). An article on the THL web page. Accessed on 3 April 2012.

[Http://demo.seco.tkk.fi/tervesuomi/item/kti:5469](http://demo.seco.tkk.fi/tervesuomi/item/kti:5469).

Vehviläinen-Julkunen, K. 2006. Hoitotieteellisen tutkimuksen etiikka. Hoitotieteen tutkimusmetodiikka. Ed. Vehviläinen-Julkunen, K. & Paunonen, M. Helsinki: WSOY.

Åstedt-Kurki, P. & Nieminen, H. 2006. Fenomenologisen tutkimuksen peruskysymykset hoitotieteessä. Hoitotieteen tutkimusmetodiikka. Ed. Vehviläinen-Julkunen, K. & Paunonen, M. Helsinki: WSOY.

Appendix 1 – Cover letter

Tiedote

Diabetesohjaus lastenosasto 1:llä Keski-Suomen keskussairaalassa- Perheiden kokemuksia sairastumisen jälkeen osastolla saadusta ohjauksesta

Opiskelemme Jyväskylän ammattikorkeakoulussa sairaanhoidon koulutusohjelmassa ja olemme tekemässä opinnäytetyötä perheiden kokemuksista diabeteshoidonohjauksesta Keski-Suomen keskussairaalan lastenosasto 1:llä.

Tämän tiedotteen liitteenä on kysely, johon voitte vapaasti kirjoittaa kokemuksistanne lastenosasto 1:llä toteutetusta diabeteshoidonohjauksesta koko perheen näkökulmasta. Tutkimukseen osallistuminen on täysin vapaaehtoista eikä tähän kyselyyn osallistuminen velvoita mihinkään. Olisimme kuitenkin hyvin kiitollisia, mikäli voisitte antaa oman panoksenne tälle tutkimukselle, sillä jokainen vastaus on hyödyksi osaston diabeteshoidonohjauksen kehittämiseksi.

Kyselyyn vastataan nimettömänä. Vastaukset käsitellään luottamuksellisesti jokaisen vastaajan yksityisyyden suojaa kunnioittaen. Vastauksista saatavia tietoja käytetään lopullisessa opinnäytetyössä ja niistä voidaan poimia myös suoria lainauksia. Kyselyn tulokset raportoidaan siten, että vastauksista ei voida tunnistaa ketään yksittäistä henkilöä. Kun tutkimus on valmistunut, kaikki kerätty aineisto tuhotaan.

Vastaukset pyydetään palauttamaan lasten poliklinikalle 16.11.2012 mennessä.

Mikäli teille tulee kysyttävää tutkimukseen liittyen, meihin voi ottaa yhteyttä sähköpostilla tai puhelimitse.

Markku Niemelä

Sanni Räsänen

F0268@student.jamk.fi

F0215@student.jamk.fi

Jyväskylän ammattikorkeakoulu
Hoitotyön koulutusohjelma

Ohjaajat:

Mari Punna

Lehtori

mari.punna@jamk.fi

Riikka Sinivuo

Lehtori

riikka.sinivuo@jamk.fi

Appendix 2 – Questionnaire

KYSELY DIABETES-HOIDONOHJAUKSESTA:

LASTENOSASTO 1, KESKI-SUOMEN KESKUSSAIRAALA

Vastauksenne käsitellään ehdottoman luottamuksellisesti. Jokainen vastaus on tärkeä osastolla toteutettavan diabetesohjauksen kehittämisen kannalta.

1. Millaisia tunteita ja ajatuksia osastolla saamanne diabetesohjaus herätti ja kuinka niihin vastattiin?
2. Millaisena koitte vuorovaikutuksen hoitoon ja ohjaukseen osallistuvien ammattilaisten kanssa?
3. Millainen kokemus hoidosta ja ohjauksesta jäi?
4. Kuinka perheenne yksilölliset tarpeet huomioitiin diabetesohjauksessa?
5. Kuvailkaa saamaanne tukea ja apua osastojakson ajalta.
6. Kertokaa vapaasti muita ajatuksia, kommentteja tai muutosehdotuksia, joita osastolla saamanne diabetesohjaus herätti.

Kiitämme yhteistyöstä!

Appendix 3 – Coding sample

PERSONAL EXPERIENCES AND FEELINGS

(Combination of themes Guidance, Improvements and Miscellaneous)

Phrases:

Guidance was good and adequate.

Guidance was decorous.

Care and guidance was very diverse.

Did not realize to expect that.

Information given in adequate amounts.

Too few nurses, when we had to constantly make them run around the ward.

I don't wish for any changes.

Sub theme *Views on the future* (originally Future)

Really good feelings also about the future.

We will make it.

SUPPORT AND INTERACTION (Originally separate themes)

Phrases:

Received support in my child's difficult illness.

They kept asking how the family was doing.

The whole family was taken care of well.

Everyone in their part helped us.

We were received very well in the ward.

Support was received all the time.

Interaction was straightforward and easy.

Chance to talk about everything possible

Nurses were warmhearted and helpful.

FAMILIES' INDIVIDUAL NEEDS

Phrases:

Our needs were paid attention to well

I got to meet, for example, a dietitian, doctors...

Help was offered in adequate amounts.

The whole family was taken care of.

We can call the ward if needed.

Appendix 4 – Research permit

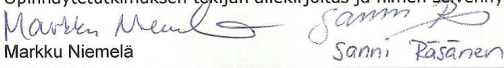
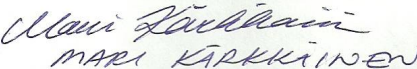
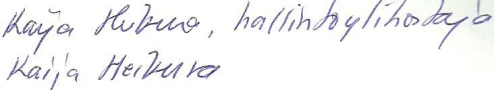


KESKI-SUOMEN SAIRAANHOITOPIIRI

OPINNÄYTETUTKIMUKSEN (YO, AMK, MUU)
TUTKIMUSLUPAHAKEMUS

TUTKIMUSNUMERO (tutkimuskoordinaattori täyttää)			
Lomake on tarkoitettu opinnäytetutkimuksen tekijöille, jotka suorittavat opinnäytetutkimukseen liittyvän aineiston keruun K-S:n shp:ssä eikä opinnäytetutkimus ole osa laajempaa tutkimusprojektia. Lomake allekirjoitetaan ja toimitetaan liitteinen tutkimuskoordinaattorille eteenpäin toimitettavaksi.			
1 Opinnäyte- työn tekijää koskevat tiedot	Tutkijan/opiskelijan suku- ja etunimi NIEMELÄ, Markku; RÄSÄNEN, Sanni		
	Nykyinen työnantaja/opiskelupaikka		
	K-S:n shp:n palveluksessa <input checked="" type="checkbox"/> Ei <input type="checkbox"/> Kyllä		
	Kotiosoite	Postinro ja - paikka	
	Puhelin toimeen	Puhelin kotiin	Sähköpostiosoite
	Yliopisto ja laitos/Ammattikorkeakoulu/oppilaitos, jossa opiskelee Jyväskylän ammattikorkeakoulu		
	Yliopiston/laitoksen/Ammattikorkeakoulun/oppilaitoksen osoite/yhteystiedot Puistokatu 35, 40200 Jyväskylä p. 020 743 8100 / 0505389210		
2 Opinnäyte- työn nimi	Opinnäytetutkimuksen nimi julkisessa muodossa/lyhyt nimi Diabetes guidance on pediatric ward 1 at Central Finland Central hospital - Families' experiences of the guidance on the ward following the diagnosis		
3 Opinnäyte- työn ohjaaja oppilaitok- sessa	Opinnäytetutkimuksen ohjaaja/t, ohjaajien oppiarvot ja yhteystiedot (sähköposti/puhelin) PUNNA, Mari		
	SINIVUO, Riikka		
	Opinnäytetutkimuksen ohjaaja on hyväksynyt tutkimussuunnitelman		
	Päivämäärä	Opinnäytetutkimuksen ohjaajan allekirjoitus ja nimen selvennys	
	28.9.2012	<i>Mari Punna</i> MARI PUNNA	
4 K-S shp:n vastuuhenkilöä koskevat tiedot	Suku- ja etunimi/virka tai toimi KARKKAINEN MARI / OSASTON TOIMIAJA		
	K-S:n shp:n vastuualue, vastuuyksikkö tai liikelaitos, jossa vastuuhenkilö työskentelee KONSERVAATIIVISEN TOIMIALUE / LASTENTAUDIT JA LASTEN NEUROLOGIA LASTEN OSASTO 1		
	Sähköpostiosoite/puhelin/gsm mari.karkkainen@ksshp.fi		

5 Opinnäyte-työtä koskevat tiedot	Tiivistetty kuvaus opinnäytetutkimuksen suorittamisesta K-S:n shp:ssä	
	Tutkimuksen kriteerit täyttävälle perheille tarjotaan kyselylomake, jonka he voivat täyttää kotona ja palauttaa diabetespoliklinikalle määräaikaan mennessä. Kyselyjä jakavat osaston henkilökunta (diabeteshoitajat) kotiutuksen yhteydessä ja polilla kontrollikäyntien yhteydessä.	
	Asiasanat (max 5 kpl) Tyypin 1 diabetes, ohjaus, perhe	
	Opinnäytetutkimuksen taso <input type="checkbox"/> Tohtorin tutkinto <input type="checkbox"/> Lisensiaattitutkinto <input type="checkbox"/> Maisteritutkinto <input type="checkbox"/> Kandidaattitutkinto <input type="checkbox"/> Ylempi AMK – tutkinto <input checked="" type="checkbox"/> AMK – tutkinto <input type="checkbox"/> Muu, mikä?	Opinnäytetutkimuksen tieteenala <input type="checkbox"/> Lääketiede <input checked="" type="checkbox"/> Hoitotiede <input type="checkbox"/> Muu terveystiede, mikä? <input type="checkbox"/> Muu, mikä?
	Opinnäytetutkimus on osa laajempaa K-S:n shp:n hanketta <input checked="" type="checkbox"/> Ei <input type="checkbox"/> Kyllä, mitä?	
	Opinnäytetutkimus kuuluu muuhun laajempaan tutkimusprojektiin <input checked="" type="checkbox"/> Ei <input type="checkbox"/> Kyllä, mihin?	
	Arvioitu aloituspv 5.10.2012	Arvioitu päättymispvm 26.10.2012
	Opinnäytetutkimuksen suorituspaikat K-S:n shp:ssä Lastenosasto 1 Lastentautien poliklinikka - Diabetespoliklinikka	
	Osallistuuko opinnäytetutkimuksen tekijä potilastyöhön <input checked="" type="checkbox"/> Ei <input type="checkbox"/> Kyllä	
	Kohderyhmä <input type="checkbox"/> Potilaat <input type="checkbox"/> Omaiset <input type="checkbox"/> Henkilökunta <input type="checkbox"/> Asiakirjat <input checked="" type="checkbox"/> Muu, mikä? Perhe	Aineiston arvioitu koko
	Aineiston keruumenetelmä <input checked="" type="checkbox"/> Kysely <input type="checkbox"/> Haastattelu <input type="checkbox"/> Havainnointi <input type="checkbox"/> Asiakirja-analyysi <input type="checkbox"/> Mittaukset, mitkä? <input type="checkbox"/> Muu, mikä?	
	Tutkija tarvitsee luvan potilastietojen käyttöön arkistosta (mm. rekisteritutkimus) <input checked="" type="checkbox"/> Ei <input type="checkbox"/> Kyllä	
K-S:n shp:n ulkopuoliset yhteistyötahot		

	Aiheuttaako opinnäytetutkimus kustannuksia K-S:n shp:lle? - <input checked="" type="checkbox"/> Ei (Tutkimusluvan myöntäjä voi vaatia selvitystä tapauskohtaisesti) <input type="checkbox"/> Kyllä (Kustannusarvio ja rahoitussuunnitelma erillisellä liitteellä)	
	Opinnäytetutkimuksen hyödyt/vaikutukset K-S:n shp:n toimintaan <input type="checkbox"/> Ei välitöntä sovellettavuutta <input checked="" type="checkbox"/> Väliön soveltuvuusarvo toimintaan, mihin/miten? Tuloksia voidaan hyödyntää lastenosastolla 1 diabetesohjauksen kehittämiseen.	
Alle- kirjoitukset	Opinnäytetutkimuksen tekijänä sitoudun noudattamaan K-S:n shp:n antamia ohjeita ja sääntöjä ja raporttoimaan opinnäytetutkimukseni tuloksista tutkimusluvan myöntäjälle	
	Päivämäärä 28.9.2012	Opinnäytetutkimuksen tekijän allekirjoitus ja nimen selvennys  Markku Niemelä Sanni Räsänen
	Päivämäärä 1.10.2012	K-S:n shp:n vastuuhenkilön allekirjoitus ja nimen selvennys  MARI KÄRKKÄINEN
PÄÄTÖS	<input checked="" type="checkbox"/> Myönnetään hakemuksen mukaisena <input type="checkbox"/> Myönnetään edellyttäen, että	
	<input type="checkbox"/> Hakemus hylätään seuraavin perustein	
	Päivämäärä 22.10.2012	Tutkimusluvan myöntäjän nimi, arvo ja nimen selvennys  Kaija Heikkinen, hallinto-ylikokoyö Kaija Heikkinen

Tarvittavat liitteet

- Opinnäytetyön tutkimussuunnitelma
 Selostus opinnäytetyön suorittamisesta K-S:n shp:ssä
 Tiedote tutkimuksesta
 Tutkittavan suostumus
 Aineiston keruulomake
 Kysely/haastattelulomakkeen saatekirje
 Kysely/haastattelulomake
 Mittarit

Lisäksi tarvittaessa

- Opinnäytetyötä suorittava muu henkilöstö
 Kustannusarvio ja rahoitussuunnitelma
 Potilastietojen luovutus- ja käyttöluvapahakemus
 Eettisen toimikunnan lausuntokopio tai kopio muun eettisen toimikunnan lausunnosta
 Tieteellisen tutkimuksen henkilörekisteriseloste
 STM:n/THL:n lupa, nro
 Muut tarv. lupakopiot
 Kopio KESLAB -sopimuksesta
 Muut mahd. sopimuskopiot (sisäiset/ulkoiset)