LAPIN AMK
Lapland University of Applied Sciences

IMPROVING GUIDANCE FOR TYPE 1 DIABETES

Factors Connected To Guidance For Children

XING QIANNI
ADU OLUWATOBI FAITH

Bachelor´s Thesis
Degree Programme in Nursing
Bachelor of Health Care

2020

LAPIN AMK
Lapland University of Applied Sciences

Abstract of Thesis

School of Northern Well-being and Service
Degree Programme in Nursing
Bachelor of Health Care

Authors Qianni Xing **Year 2020**
Oluwatobi Faith Adu
Supervisor Heidi Korhonen, Seppo Kilpiäinen
Commissioned by Mehiläinen Länsipohja Central Hospital, Diabetes Nurse Henna Holopainen
Title of Thesis Improving Guidance Quality for Children With Type 1 Diabetes
Number of pages 48 + 22

In Finland, Diabetes is seen as a major public health problem. It is said to affect the quality of life of those who have the disease and it increases the mortality rate in the country. According to the National Institute of Health and Welfare Finland, type 1 Diabetes in Finland is more common than in any other country due to the Finnish gene family. Children who are diagnosed with type 1 Diabetes usually receive guidance from the nurse. This helps them to manage their Diabetes and live a relatively normal life. Many of these children, however, do not fully receive the proper guidance for their condition. There might be certain factors that could explain this. The purpose of this thesis is to explore the factors which could influence the quality of guidance. The aim of this thesis is to help health care-givers to improve guidance of children with type 1 Diabetes.

A multi research method, including a literature review and a qualitative analysis was used as the research method in this thesis. Reliable, evidence-based data were collected from JBI, PubMed and CINAHL. All articles were written in English. Eleven people participated in the interview. These participants were interviewed at the outpatients clinic of a central hospital in Northern Finland. The collected data was analyzed by using qualitative inductive content analysis.

From the study, it was found that communication, guidance methods, family influence, age, gender, caring environment, nurse's attitudes, nurse-patient relationship, psychology, race and multiple ways of knowing are all factors connected to guidance.

Keywords: guidance, type 1 Diabetes, children.

CONTENTS

1 INTRODUCTION

Type 1 Diabetes is a life-long insulin-dependent condition which is caused by the pancreas producing little or no insulin. That is why patients with type 1 Diabetes diseases are easily hungry, thirsty, lose weight and fatigued. There are various causes of type 1 Diabetes including family history, genetic factors and age related problems (Ruxer, Mozdzan, Czupryniak & Loba 2003).

In Finland, Diabetes is seen as a major public health problem. It affects the quality of life of those who have the disease and increases the mortality rate in the country (Marja & Klass 2006, 5, 9). Presently in Finland, the number of children and young people developing Diabetes is growing higher. Between 2006−2011, the mean incidence of type 1 Diabetes in children under 15 years was 62.5% /100,000/year (Hakkaraine et al. 2017, 3). Type 1 Diabetes is more common in Finland than in any other country, apparently due to the Finnish gene family. Approximately, there are about 50 000 people with type 1 Diabetes (National Institute of Health Welfare 2015) and about 350 000 people with type 2 Diabetes in Finland. About 4 000 children under the age of 15 have Diabetes. The number of undiagnosed cases of type 2 Diabetes is estimated at 100 000 (Finnish Diabetes Association 2019).

Children who have type 1 Diabetes should follow hospital guidance which helps them to manage their Diabetes and live a normal life. However, many of these children do not fully receive the proper guidance. The reason for choosing this topic is to help hospital nurses understand how to administer proper guidance of children with Diabetes.

Family-centered care is the main direction in pediatric health care. Young children who are not able to receive guidance from health-care givers will be supported by family members which means that guidance skills that are applied to all patients should be considered by nurses. (Bowden & Greenberg 2010, 6-9.)

The purpose of this thesis is to explore the factors which could influence the quality of guidance. The aim of this thesis is also to help health care-givers to improve guidance for Children with type 1 Diabetes. The research question of this thesis is, what factors could influence the guidance quality for children with

type 1 Diabetes?

The purpose of this thesis is to explore the factors which could influence the quality of guidance. The aim of this thesis is also to help health care-givers to improve guidance for Children with type 1 Diabetes. The research question of this thesis is, what factors could influence the guidance quality for children with type 1 Diabetes? Multi-methods comprising of literature review and qualitative analysis were used as the research method.

For this thesis work, Jean Watson's theory (2008) was used as the theoretical framework of the thesis. Jean Watson's theory was chosen because it pointed out important factors that improve guidance in a nursing environment (Watson 2008, 1-7).

This thesis is written for the benefit of the nurses because it is important for nurses to understand the various guidance skills. To ensure that diabetic children are able to manage their Diabetes and improve their quality of life, it is the responsibility of the nurse to guide them. Updated nursing guidance skills will make the nurses' guidance to be easily accepted by patients.

2 BACKGROUND AND GUIDANCE OF DISEASE

2.1 Type 1 Diabetes in Children

Type 1 Diabetes is also known as insulin-dependent Diabetes or juvenile Diabetes, since it is mostly developed in childhood or youth. It is caused by insufficient production of insulin by the pancreas, so that the body cannot regulate blood sugar level by transferring blood sugar to body energy (Centers for Disease Control and prevention 2020). Patients with unmanaged type 1 Diabetes are easily thirsty, extremely hungry, have unexplained weight loss, bed-wetting in children who previously did not wet the bed during the night, feel tired all the time, abdominal pain and tingling (Kahanovitz, Sluss & Russell 2017, 37-40). If children are suspected to have type 1 Diabetes, laboratory tests are necessarily applied to diagnose the disease. This means that the blood and urine sugar level tests and the ketone bodies in urine should be checked. An oral or venous glucose tolerance test may help in diagnosis. Once the Diabetes is diagnosed, the guidance for treating and maintaining the blood sugar levels should be provided in the hospital, in order to get into balance, assess the patient's condition and to provide a normal life out of the hospital environment (Kuusisto et al. 2020).

Type 1 Diabetes is a life-long disease, it cannot be fully cured. The key to managing type 1 Diabetes is to maintain the balance of the amount of insulin and blood glucose levels in order to prevent low blood sugar or ketoacidosis. Ketoacidosis happens when the amount of ketone bodies increase because of muscle fats metabolism that leads to blood becoming acidic (Ghimire & Dhamoon 2020). It may cause symptoms like nausea, tachycardia, chest pain or even unconsciousness (Kuusisto et al. 2020). Extra insulin is needed as medication for patients with type 1 Diabetes. There are four types of insulin including rapid-acting, short-acting, intermediate and long-acting insulin. Insulin should be taken by injection, or if a patient needs constant monitoring or small doses of insulin at one time, another delivery means such as infusion with an insulin pump should be provided to the patient (The Global Diabetes Community 2019). Rapid and short acting insulin are mainly injected less than 30 minutes before meal, the dosage depends on the amount of carbohydrates to be taken in every meal. Intermediate insulin usually should be given 1-2h before bed or

meal-time, and it cannot be mixed- with long-acting insulin and glulisine. Long-acting insulin is usually given once a day depending on the prescription of doctors (Adams & Holland 2011,678-683). Patients need to be educated before they can maintain the glucose-insulin balance themselves.

There are several factors that may influence the needs of insulin including exercise, fever and other stressful states of the body, alcohol use, puberty and the time of the day (Kuusisto et al. 2020). Research has proved that physical activity makes the body more sensitive to insulin, so it decreases the need of insulin (Bird & Hawley 2016). The stress hormones adrenaline and cortisol produced during fever and stress period increases the blood sugar level for patients with type 1 Diabetes and the needs of insulin injections (Scott 2011). Moderate amounts of alcohol consumption, even a short period, can obviously lower the glucose level which decreases the usage of insulin (White 2017, 433-435). Children with Diabetes during puberty usually increase their insulin requirement because increase in the rate of growth hormone secretion during puberty period decreases insulin sensitivities (Bloch, Clemons & Sperling 1987).

With proper guidance by health care teams, patients should be able to manage and monitor blood sugar levels independently. The target range of sugar level in plasma before meals should be between 4-7mmol/L, in 2 hours after meal, the number should be lower than 8-10mmol/L. HbA1c level generally should be less than 53mmol/L, and it will be checked every 3-6 months depending on the instruction given by diabetic nurses and doctors. (Kuusisto et al. 2020) Maintaining blood sugar in a right level is important in preventing its complications, even some problems won't start immediately, however, long-term high blood sugar level may result to diabetic retinopathy, neuropathy, atherosclerosis, diabetic nephropathy, and diabetic foot ulcer (NHS 2018).

Children with type 1 Diabetes should eat sufficient nutrition to ensure their development. However, limitations in food intake that contain saturated fat, added salt, added sugars and alcohol should be taken into account. Eating regularly and drinking sufficiently is always necessary for children (Australia National Health and Medical Research Council 2016). Exercise is also encouraged, since it is important in balancing lifestyle and maintaining health for children with type 1 Diabetes. (Kuusisto et al. 2020)

2.2 Diabetes Guidance

Self-management has been described as the cornerstone of care for Diabetes (Suomalainen Lääkäriseura Duodecimi, Suomen Sisätautilääkärien yhdistyksen & Diabetesliiton Lääkärineuvoston asettama työryhmä. 2020). Self-monitoring of the blood sugar and usage of the insulin is essential for the good treatment of type 1 Diabetes (Parikka 2018). Käypähoito care guidelines recommend that the aim of self-monitoring is to prevent acute Diabetes complications and comorbidities, to support coping and improve quality of life. Adequate guidance and support, especially during the illness phase, are important for the success of self-care in the future because they improve quality of life and prevent acute complications and associated illnesses. (Suomalainen Lääkäriseura Duodecimi et al. 2020)

Käypähoito care guidelines recommend that the primary focus of Diabetes guidance is on the patient and the family. Guidance could be a multidisciplinary collaboration (doctor, nurse and other healthcare professionals) (Suomalainen Lääkäriseura Duodecimi et al. 2020). However, Diabetes nurses are the ones primarily responsible for Diabetes guidance (Rasanen & Niemelä 2012, 6). By educating patients on self-care and monitoring, it is possible to improve the sugar balance of diabetics, especially in children (Parikka 2018).

The patient's needs during guidance should be assessed so that interventions can be focused on the essential challenges. A guilt-free approach helps identify key challenges and build a collaborative relationship. Interaction and guidance should be empowering and supportive of a sense of ability and problem solving. Motivational interaction skills are an important element in guiding self-care and behavioral change (Young-Hyman et al. 2016, 2126).

The patient's understanding of his or her ability to treat Diabetes is linked to improved self-care and treatment outcomes, and should be the goal of assessment and treatment planning (Suomalainen Lääkäriseura Duodecimi et al. 2020).

A high quality guidance is one that is tied to the context of the instructor and the one receiving the guidance. It is an active and a goal-directed activity, where the instructor and the one receiving the guidance are interacting. When a

high-quality guidance is done properly, it is effective, it supports managing with the disease, promotes quality of life and commitment to treatment, and adds a feeling of safety and satisfaction towards treatment. It also lessens anxiety and fears, promotes self-care at home and lessens the usage of healthcare services (Rasanen & Niemelä 2012, 11).

The beginning point for high-quality guidance is a patient-oriented approach. It is based on showing respect for the patient's dignity and caring for him/her as a person. It allows mutual respect and helps common understanding to be reached (Rasanen & Niemelä 2012, 10). It is important to understand that patients differ from one another in several ways, therefore their needs and styles for learning are different (Rasanen & Niemelä 2012, 10). These features should be considered in guidance.

Two guidance approaches will be discussed in this thesis; the patient oriented approach and the family centred care approach. Patient oriented approach is chosen because it is the centre of good guidance (Rasanen & Niemelä 2012, 10) While the family centred approach is chosen because it is the centre of paediatric guidance in nursing. Young children who are not able to receive guidance from health-care givers will be supported by family members which means that guidance skills that are applied to all patients should be considered by nurses. (Bowden & Greenberg 2010, 6-9.)

2.2.1 Patient Oriented Care Approach

As stated earlier, the patient oriented approach is the centre of any high quality guidance. It is based on respecting the patient's dignity and caring for him/her as a person. It enables mutual respect and tendency to deal with the issues so that a common understanding is reached (Rasanen & Niemelä 2012,10). Patient-centered care has been found to be associated with improved patient outcomes, which includes improved self-management, patient satisfaction and medication adherence (Glyn et al. 2014, 270). Involving the patient in guidance results in gaining relevant information, empowering the patient, and may improve the patient's health and behaviour (Coulter & Ellins 2007, 24 - 27).

Every patient has his/her own personality, therefore the needs and styles for learning are different, this could also be a challenge for guidance (Rasanen &

Niemelä 2012, 10). Engaging the patients in guidance should be initiated in a stepwise approach through which both parties can learn together (that is the nurse learning about the experience of the patient, and the patient learning from the nurse also) and identify the method that works best for the patient. The nurse must aim to provide support, define roles, manage expectations, and give feedback to ensure that engagement is mutually beneficial (Wit, Cooper & Reginster 2019, 1095).

2.2.2 Family Centred Care Approach

Everyone defines family in his/her own way. For example, in Nigeria family is beyond father, mother and siblings. Family extends to the relations, best friends etc. In paediatrics guidance, family centred care is the focus, this is because young children who are not able to receive guidance from the nurses could be supported by their family members (Bowden & Greenberg 2010, 6 - 9).

Family centred care is a partnership approach to healthcare decision making between the family and the healthcare provider. It is considered to be the standard of pediatric healthcare by many clinical practices, hospitals and healthcare groups (Kuo et al. 2012, 297). Family centred care has been found to be associated with improved health and well-being, improved satisfaction by the patients (Kuhlthau et al. 2011, 136).

In family centred care approach, the nurse acknowledges the family as part of the child's life, builds on the strengths of the family, supports the child in participating in the guidance (Kuhlthau et al. 2011, 136 - 137). The general principles are sharing information, partnership and collaboration, respect and honour (Kuo et al. 2012, 298). In Family centred care, family members of the child are involved with their children. Therefore, this moves beyond patient-nurse interaction but considering the needs of the family also (Shields et al. 2006, 1320).

In pediatrics it is assumed that a child's main source of strength and support is his/her family. Also, in clinical decision making family's perspectives and information are of great importance, as they are the experts of the child's everyday life (Pettoello-Mantovani et al. 2009). Since the child and his/her family are responsible for self-care, it is important for the family to take part in guidance.

Through this, they get information about the disease and will be able to discuss their thoughts and feelings (Rasanen & Niemelä 2012, 12).

A systematic review was done in the USA by Kuo and his colleagues about Family Centred Care. From their research, it was evident that Family Centred Care increases the family understanding, sharing in decision making and their sense of respect from the medical team. It was also suggested that Family Centred Care could increase a professional's sense of teamwork, and may generate new previously unknown information from the family (Kuo et al. 2012, 301).

3 CHILD DEVELOPMENT IN RELATION TO GUIDANCE

The role of the child in Diabetes management is important; to provide optimal care, Diabetes nurses should understand the course of a developmental span and bear that in mind while implementing guidance. The developmental course is that which belongs to the normal development and which a person needs to go through before moving on to the next developmental level. The features of these developmental courses include physical, emotional, social, mental, and moral areas of development. The development of the brain affects these developmental courses (New York Office of Children and Family services 2015, 5; Rasanen & Niemelä 2012,14; Markowitz, Garvey & Laffel 2015, 231 - 238).

3.1 0-2 Years Old

From newborn till 2 years old, children use their senses to learn and grow, they gradually separate themselves from the environment and become more active in learning the surroundings. At about 4 months old, primitive reflexes disappear, babies are able to control their bodies during seating position, they start trying to turn their bodies, and grasping ability also develops quickly. At about 8 months, protective reflexes were built to make sure children were able to sit without support. Children between 18-24 months belong to the sensorimotor period, they are quick to learn new things, they normally walk without help, pincer grasp also develops during this stage. However, children only can understand the limited things, like the behaviors which could be perceived directly. (Kuusisto et al. 2020; Edelman, Kudzma & Mandle 2014, 1468-1530)

Children develop their language system by mimicking or copying sound from others. It is strongly influenced by the language they hear spoken around them. At 1-2 months old, children would be able to build eye contact with their parents, and able to react or locate the source of sounds. Starting with vocalising and gurgles, children could speak their first word at about 10-14 months, at 1.5 years old, children should be able to name items and simply recognize or respond to their caregiver. Neology development and life experience have a big effect on their language or activity development, for this reason, regular examination for children is important to make sure their growth follows with average growth curves. (Kuusisto 2020; Edelman et al. 2014, 1468-1530)

3.2 3-6 Years Old (toddler)

In this period, the brain structures grow rapidly, language, learning skills, fine and gross motor skills are developed. The children have the ability to imitate more complex actions, and show increasing use of their imaginations. They are usually observing their environments and themselves, they like to experience that their actions are meaningful, they are also self confident (Markowitz et al. 2015, 231 - 238; Rasanen & Niemelä 2012, 18).

Due to the formation of their sensory and language skills, the children are able to recognize many letters, their vocabulary increases to about 1500 - 2000 words, and end up making a complete sentence (Susan 2013, 7).

Children become skilled in basic physical activities including running, jumping, early throwing, and kicking, they could more specifically draw or write. They also become skilled in other basic activities like dressing themselves. They can balance on their feet with their feet closed. This is because of the development of their fine and gross motor skills (Susan 2013,7).

Guidance is usually given to the parents, however, there's always a possibility for the children to participate, yet, this can be made possible based on the interest of the child (Rasanen & Niemelä 2012, 18).

3.3 7 - 12 Years Old (school age)

Children at this stage increase their ability to learn and apply skills, become competitive, deal with their friends. They also develop and test their beliefs that helps them to guide their present and future behaviours. The brain at this stage increases its capacity for moral reasoning, focused on setting goals and processing information. Children have the ability to distinguish between what is right or wrong, understand the consequences of their actions to some extent (New York Office of Children and Family Services 2015, 35-46).

Their development is also affected by parenting, need and ability to create experience of their own capability, environment and feeling of frustration (Rasanen & Niemelä 2012, 16). Children at this stage maybe affected by any underlying disease because it gives them loneliness, extreme difficulty concentrating in school, difficulties in coping among friends which gives them

limitations that may cause negative behaviour towards their treatment (Rasanen & Niemelä 2012, 16; New York Office of Children and Family Services 2015, 35-46). Children at this stage can follow about five commands of words in a row, they can also receive guidance with their parents in the hospital. Their technical skills are also improved, that is they can practice how to inject themselves with insulins under the supervision of their parents (Rasanen & Niemelä 2012,16).

3.4 13 - 17 Years Old

Adolescence is the transitional period between the start of puberty and adulthood in human development and marks a time of great change in both physical and psychosocial realms. Adolescents experience rapid physical growth and sexual maturation. An increasing awareness of sexuality and greater preoccupation with body image are psychosocial hallmarks of the adolescent stage. Identity formation is a central developmental challenge for adolescents. As adolescence progresses, individuals acquire skills needed to carry out adult roles and develop expanded capacity for abstract reasoning. Adolescence is also a period of risk during which social contexts and peer relationships exert powerful influences (Markowitz et al. 2015, 231 - 238).

Children in this age group create a personal identity based upon the combination of their values. They develop a sense of self in relation to society, opposite sex, future, ideas and the world in general (New York Office of Children and Family Services 2015, 55 - 59). Self perception may become an issue for them because of their disease and they see themselves as part of their disease, this could make them feel ashamed and feel guilty of getting ill and feel different from others. This sometimes make them to be socially isolated from their peer groups. (Rasanen & Niemelä 2012, 16)

They try to accept physical development and reach emotional independence from their parents and other people. Their brains usually undergo some significant changes. These changes affect their behavior, thinking and emotions. The response to their motivations is always long,their impulse control is always slow. This is the reason so many teens take unnecessary risks and make poor decisions (New York Office of Children and Family Services 2015, 55 - 59). They usually have conflicts more with their parents and those older than them because they feel controlled by authorities and don't find it pleasing when

inquiries are made into their private lives and self-care (Rasanen & Niemelä 2012, 16).

4 THEORY OF Dr. JEAN WATSON (1940 -- present)

For this thesis work, Jean Watson's (1940 -- present) theory was used as the framework of the theory. Jean Watson's theory proposed that communication, helping-trusting caring relationships, caring-healing environment, multiple ways of knowing, family-centered care are important elements of nursing care (Watson 2008, 34). This theory was used as an approach to organize and analyse the factors that affect nursing guidance for diabetic children. Nursing guidance is provided for preventing, alleviating and managing diseases. This implies that guidance in nursing care is holistic. In the concept of nursing, holistic health care is the focus of the practice of caring. Nursing is defined as a human science of persons and human health-illness experiences that are mediated by professional, personal, scientific, and ethical human transactions (Angelo 2016).

Watson's theory argues that a help-trust relationship promotes interpersonal teaching-learning, and provides support to assist with human needs (Angelo 2016). Nurses have responsibility to give support, education and motivation to the patient. Creating long-term therapeutic relationships is the corestone for patients to accept care from nurses and adhere to it (Adams 2012, 18, 25). In that way, nurses will be able to help them to manage their diseases giving them the proper guidance. There's a high probability of patients to disclose and speak out their thoughts if they trust the nurses, decision making will be shared leading to high quality of guidance and satisfaction from the patients. However on the other hand, a lack of trust will get the patient anxious or frightened, there could be resistance to acceptance of guidance from the nurses, the guidance quality will be affected, the nurse won't offer much help and the outcome of care will be poor. (Jarva & Haavisto 2018, 8 -9; Allison & Chaar 2016)

Watson believed that good communication is important in guidance (Watson 2008, 24). Good communication with the patients is the basis of creating a positive trust relationship with them (Holmström, Häggström & Söderberg 2018, 117). This communication is built with the patient by integrating respect, empathy, trustfulness and confidentiality into the interaction (Bakari & Doreen 2016, 8). Communication skills such as concentrating on positive solutions and motivation, strengthen interaction between the nurse and the patient (Christie et al. 2016, 3), help the nurse to encourage involvement in care and improve psychological

adjustment to care (Cespedes-Knadle & Munoz 2011,289). This will promote the patient participating in the care and the result of the care will be positive (Costa et al. 2018,3280). Language barrier is a factor that can weaken communication between the nurse and the patient (Cespedes-Knadle & Munoz 2011,289), which results in resistance to guidance from the nurse and affects the skills of the nurse to meet the needs of the patient (Tavallali, Kabir & Jirwe 2013,255).

Dr. Watson's theory (2008) argued that creating a caring-healing environment is an important nursing environment for guidance (Watson 2008, 24). This environment is defined as comfortable, beautiful, and peaceful (Durgun, Okumus & Lash 2015, 26). Patient guidance is very important for building the patient's knowledge and preparing them for self management (Anne-Louise, Febe, Eva & Elisabeth 2015, 2). A good nursing environment that is comfortable, peaceful and beautiful helps in accomplishing this because it is empowering, safe and satisfying (Wei, Sewell, Woody & Rose 2018, 290). After the caring-healing environment is built, children will experience it by sensors which help them understand new information and navigate new environments (Sfandyarifard, Sutrisna & Tzortzopoulos 2010, 96) , while receiving guidance from the nurses, child‘s sensory receptors will be converted into a form that the brain can interpret and store in this environment (NHS Estates 2004, 41).

Watson explained the importance of understanding the family as a person and the presence of family in care (Watson 2008, 34). Family centred care which is an aspect of paediatric nursing is important to be considered in guidance, because it acknowledges the family as part of the child's life, supports the child in participating in the guidance (Kuhlthau et al. 2011, 136) and provides a better degree of adherence and sustainability for the children by motivating them, improving their health-related quality of life and making the outcome of the guidance positive (Distelberg, Williams-Reade, Tapanes, Montgomery & Pandit 2014, 194–213). Since the family are directly or indirectly involved in the care because responsibilities of self-management are transferred to them (Rechenberg, Whittemore, Grey, Jaser & TeenCOPE Research Group 2016, 126). It is important that the nurse gives parents support through chronic disease management education and psychosocial counselling (Pelicand, Fournier, Rhun & Aujoulat 2012, 307), in order to reduce disease-related parental stress and avoid conflict in the family system. (Cespedes-Knadle & Munoz 2011, 280;

Nieuwesteeg et al. 2016,335)

One of the core concepts of Watson's theory (2008) that is proposed to be an important element of nursing care is multiple ways of knowing (Watson, 2008, 34). There are four ways of knowing; science of nursing, art of nursing, personal knowledge gained through experience and ethics (Gurm 2013, 2-6). This is important in nursing care because nurses care for different people with different needs and backgrounds. In patient education, race and ethnicity play an important role and may explain some of the differences in care (Rechenberg et al. 2016, 2). For Example, culturally sensitive care may affect the patient's acceptance of guidance in a multiethnic society. This could be because in a multiethnic society of minority ethnic nurses who don't speak the first language of the patient, the nurses could find it difficult to adjust to the culture of the patient. However on the other hand, the nurse's cultural background could have no effect on the nursing care, if the nurse respects the patient's culture and is able to support the patient through his/her professional knowledge, nursing skills and competence as well as the personal attributes of the nurse, thus the needs of the patient can be met or satisfied. (Tavallali et al. 2013, 225,258)

Jean Watson's theory (2008) was chosen because it gives us the theoretical support to give guidance in a humanistic way. Angelo (2016) explained that Watson's theory is focused on human beings as valued people to be cared for, respected, nurtured, understood and assisted. Human beings cannot be healed as objects (Durgun et al. 2015, 26). Based on these facts in her theory, it is believed that communication, helping-trusting caring relationships, caring-healing environment, multiple ways of knowing, family-centered care are important factors in giving guidance to patients (Watson 2008, 34).

5 PURPOSE, AIM AND RESEARCH METHOD

Research aim tells about the intention and the desired outcome of the thesis project, while the purpose tells about the motive and the tasks that need to be accomplished to meet the desired outcome of the thesis project. (Erkkilä 2019, 18)

The purpose of this thesis is to explore the factors that could influence guidance for type 1 Diabetes children. The aim of this thesis is to help health care-givers to improve guidance for children with type 1 Diabetes.

In the thesis, the following research question will be asked:

What factors could influence the guidance quality of children with type 1 Diabetes?

6 METHOD OF IMPLEMENTATION

6.1 Data Collection Method

Multimethod research including literature review and qualitative research are used as the method of research implementation in this thesis. Multimethod is a research strategy that is used to analyse topics of the same generic type either qualitative or quantitative (Jyväskylän Yliopisto, 2014). In the case of our thesis, a literature review and a qualitative research are used to generate a qualitative result.

6.1.1 Literature Review

Literature review is used to construct the context of the thesis. Literature review is a research method that involves the selection of evidence-based articles, journals or research papers to provide information, ideas and evidence on a topic (Moule & Goodman 2009, 138). It involves collecting and integrating previous research so that it clarifies and gives a good theoretical base for a research work (Snyder 2019, 338). Literature review helps to gain an understanding of previous research based on the topic, and to detect areas in which more research is needed (Moule & Goodman 2009, 138; Snyder 2019, 338). For the purpose of this thesis, literature review was used to provide a theoretical basis for the interview method.

For this research, a descriptive literature review was used. A descriptive literature is focused on divulging an interpretable pattern from an existing literature. The procedures of this method are usually systematic which include searching, filtering, and classifying processes. (Yang & Tate 2012, 7)

The electronic databases (JBI, PubMed, CINAHL) from the school library of the Lapland University of Applied Sciences were used including limited to full text. The term ‘pediatric Diabetes’, ‘Diabetes education’, ‘factors influence guidance’ ‘Type 1 Diabetes guidance children’, ‘pediatric Diabetes’, ‘Diabetes’, 'pediatric guidance’, ‘Pediatric education' and ‘pediatric Diabetes education’ were used as the keywords in searching. Also, search strategies were used to help improve search including search operator ‘AND’ (For example, in CINAHL, ‘pediatric Diabetes education’ ‘AND’ ‘Diabetes education’ ‘AND’ ‘factors influence guidance’).

Over the last decade, only a few articles summarized factors that probably influence the guidance for diabetic patients, several reviews have evaluated complications of type 1 Diabetes, the relationship between Diabetes and obesity, educational, psychosocial and family interventions for type 1 Diabetes.

Researchers collected related factors from different articles and reorganized them based on the theory that was used. Researchers have found 100 results from JBI, 756 results from PubMed and 903 results from CINAHL in a total of 1759 articles related to keywords. In the end, only 64 articles meet our search criteria and were selected.

This thesis used the inclusion and exclusion criteria for literature review data collection. Inclusion and exclusion criteria define what can be included or excluded from a study (Rakesh 2016, 7). Data was selected by checking the characteristic prospects that were included in our subject and disqualifying those that were not included. The criteria used for the search are explained in the table (Table 1) below :

Table 1. A summary of Inclusion and Exclusion Criteria

Search Criteria	Inclusion Criteria	Exclusion Criteria
Language of Literature review Material	English language	Other languages than English
Data sources	Scientific resource	Unscientific resource
Time Frame	From January December 2010 to December 2019	Material earlier than Jan. 2010 or later than Dec. 2019
Content/keyword	Materials related to type 1 Diabetes guidance for Children	Materials not connected to topic of our thesis

Language of questionnaire	Questionnaire filled in English or Finnish	Questionnaire filled in other languages.
Participants	Children (age < 18 years old)	People over 18 years old
Articles review for literature	only free of charged articles were used in our literature review	Articles which need to be paid.
Material Edition	For the same material. The newest edition was used.	Editions other than newest one

6.1.2 Participants Interview

The interview method is the most common data collection method used in qualitative research. There are mainly three types of research interviews: structured, semi-structured and unstructured. It is used when needed to put a deeper understanding to the participants´ expression. (Gill, Stewart, Treasure & Chadwick 2008, 291-295.)

Two kinds of questionnaires were used for the interview: open-ended questionnaire and closed-ended questionnaire (Appendix 1 and Appendix 4). Questionnaires conducted for children in the polyclinic were written in both English and Finnish. Children with type 1 Diabetes who were willing to join this research were chosen as participants. Young children who have no ability to join or understand research, were represented by their parents or other guardians.

Participants were given two questionnaires (open - ended question and closed ended questions). Open ended questionnaire was used to help the participants to reveal their own opinions about the factors that affect the guidance quality. The closed ended questionnaire on the other hand was used to explore the participants' opinion about the factors that are important to them from the results

that were summarized from the literature review. Questions that were used were extracted from the researchers' literature review study. 11 participants were involved in the study, 10 of them gave answers to the open ended questionnaire, while all of them gave answers to the closed ended questionnaire. Participants gave answers to the questions based on their understanding or with the help of the supervisor.

6.2 Data Analysis

In this thesis, an inductive content analysis method was used as the method for analyzing data for both interview and literature review. Content analysis is chosen since it is the simplest form of data analysis, it involves retrieving data by labelling it. In data analysis, the content of the data is explored, and reduced by a process called `coding` (Moule & Goodman 2009, 349-351). Coding is converting data from other forms into a textual form based on study objectives (Gaur & Kumar 2017, 6). This coding scheme was applied to the entire body of text for the purpose of extracting uniform and standard information from our data. In each article, there's at least one factor that could affect guidance mentioned. However, some articles mention two or more factors which may affect guidance, so that articles may be coded repeatedly in several groups according to its contents. Our coding system included 11 ratings of factors that influence guidance according to their contents (Table 2), which are: communication, guidance methods, family influence, age, gender, caring-healing environment, nurses attitude to care, patient nurse relationships, patient's psychological health, race and other factors. This information was then used to draw our own inferences or combined with other data for conducting further statistical analyses (Gaur & Kumar 2017, 6).

Table 2. Coding for Content Analysis

Ratings	Factors affect guidance for type 1 Diabetes Children	Numbers Of Articles Used
1	Communication	16
2	Guidance Method	31

3	Family Influence	32
4	Age Specific Issues	12
5	Gender	4
6	Caring Environment	12
7	Attitudes of Nurses	11
8	Patient-Nurse Relationship	10
9	Patient Psychological Health	14
10	Race,Cultural and Religious Beliefs	9
11	Multiple Knowing	8

Although qualitative content analysis can be used in either an inductive or a deductive way, inductive content analysis was used (Elo et al. 2014, 1-2). The inductive content analysis is a qualitative method of content analysis which gives the researcher the enablement to reduce the contents of interest into groups or themes. This analysis uses inductive reasoning, in which a wide generalization is made from observation of specific contents (Erkkilä 2019,24). There are three stages of inductive content analysis, which are: preparation, organization, and reporting of results. The preparation stage comprises useful data collection for content analysis, drawing useful information out from the data and sorting out the unit of analysis (Elo et al. 2014, 1-2). The inductive content analysis helps to arrange the qualitative data. This is achieved through a process called the organization phase. The organization stage comprises open coding, creating categories and abstraction (Elo & Kyngäs 2008, 109).

7 FINDINGS AND RESULTS

The results of this research are planned to answer the question: what factors could influence the guidance quality for children with type 1 Diabetes? The authors of this research obtained solutions to this problem from relevant articles after reviews of literature and interviews were done for the target group.

7.1 Literature Review Results

In total there are 1759 articles found related to keywords that are used in searching. 64 articles were selected for analyzing. Factors that could influence guidance quality for children with Type 1 Diabetes were divided into 11 categories: Communication, Guidance methods, Family Influence, Age, Gender, Caring environment, Nurses' attitude, Patient-nurse relationships, Patient's emotional and psychological health, Race and cultural beliefs, and Multiple knowing. Articles were coded repeatedly in several groups according to its contents.

7.1.1 Communication

Communication is important to reach a positive outcome of guidance. According to our reviews, 16 studies reported that a contributing factor to the quality of guidance is communication.

Communication problems are one of the most prevalent barriers to guidance (Valenzuela et al. 2014,1369, 1371-1374). Communication skills that have a focus on the identification of the skills of the children and collaborating with them shows effectiveness in guidance (Christie et al. 2016, 3). It was also suggested in several studies that the participants explained that good dialogue and communication with the children and their parents were important and made their experiences a positive one (Holmström et al. 2018, 116-117; Reichert et al. 2017, 487; Sliva, Pennafort & Queiroz 2016, 1594-1597; Livesley & Long 2012, 1293-1294; Lowes et al. 2014, 55-60; Marcellus et al. 2015, 15-16).

The nurse could encounter patients that have different communicative and cognitive abilities quite different from others, this could also affect guidance quality. However, some communicative skills such as drawing could give a positive influence on guidance (Vanelli et al. 2018, 1-2, 6; Marker, Monzon,

Goggin, Clements & Patton 2019, 2,7). Ineffective communication, inability to explain and use of complicated medical languages give patients inaccessibility to understand the guidance of the nurse (Costa et al. 2018, 3280, 3283-3284; Sliva et al. 2016, 1594-1597).

Children are good at distinguishing different ways of communications, the emotional quality of expression with them will affect how well they accept guidance. Children are sophisticated with both verbal and non verbal expressions, however, when they face incongruent communications (for example, criticizing with smile or praising with frown), they tend to choose the negative message of the expression which may affect their motivation to cooperate with the nurse in receiving guidance (Chisholm et al. 2012, 86-87).

Language barriers have a big influence on the interaction between the nurse and the patient especially if the patient is of a different race. Reports suggested that these frustrated both the nurses and the patients. (Cespedes-Knadle & Munoz 2011, 280-289; Tavallali et al. 2013, 255-261; Valenzuela et al. 2014,1369, 1371-1374; NCC-WCH 2015, 80-86) While providing guidance, nurses should follow the words and languages used by the family members, it is important in helping patients understand the disease and adhere to guidance (Distelberg et al. 2014, 194–213).

7.1.2 Guidance Methods

The method of guidance affects the quality of guidance and the reception of guidance by the children.

Studies revealed that using video contents, video games or computers to guide children was very attractive for the children and their parents. Many of them benefited from it and found it is informative and made guidance acceptable by the children. (Marker et al. 2019, 2,7; Nguyen 2016, 2; Islam 2018, 2).

Simulator as a common method was used to explain blood glucose monitoring, insulin practice and stress response in some studies. The simulator helped the participants to have a better understanding of care and perform them willingly, it helped to build confidence in self-management, and eliminate nervousness in attaining Diabetes knowledge and skills practice (Sullivan-Bolyai, Crawford, Johnson, Huston & Lee 2012, 121-128; Ramchandania et al. 2016, 1365). It was

perceived to be realistic and helpful which yielded positive outcomes of guidance. However, there were other perceptions that called it creepy, scary and strange (Sullivan-Bolyai et al. 2012, 121-128).

Peer group interaction is also a method that affects guidance (Altundag & Bayat 2016, 1013). Peer guiding as a useful method of guidance has been proven as a good method to guide young people with Diabetes (Chafe, Albrechtsons, Hagerty & Newhook 2015, 4-6; Shepherd 2013, 1037-1039; Adams 2012, 18-25; Kazemi, Parvizy, Atlasi & Baradaran 2016, 2,10-13). This method allows disease-mate to be involved in guidance to support diabetic children which could help them to build self-confidence, to develop their autonomy and increase their knowledge about the disease. However, peers cannot provide guidance, but they can help to increase adherence to guidance (Kazemi et al. 2016, 2; Altundag & Bayat 2016, 1013).

Studies mentioned that different approaches such as use of narratives, problem solving approach and cognitive-behavioral coping strategies have been proven to be effective in improving adherence to guidance (Mulvaney et al. 2010, 140 & 141; Monaghan, Hilliard, Cogen & Streisand 2011, 224-232). Motivational interview and solution focused strategies are also guidance methods that yield positive behaviour change in children and their families (Pelicand et al. 2012, 304-309; Christie et al. 2016, 2).

7.1.3 Family Influence

Parents also play an important role in the guidance of Diabetes (Lohan, Morawska & Mitchell 2015, 804). Several articles revealed that the parent's involvement in the guidance affects guidance especially for adolescents (Katz, Volkening, Butler, Anderson & Laffel 2014, 142-150).

Reduced parental involvement in guidance has been predicted to have negative effect on guidance, however, parental involvement in care has produced positive influence and improvements in adherence to guidance by children (Iversen, Helland, Bjertnaes & Skrivarhaug 2018, 2; Naughton et al. 2014, 2; Morrison, Dashiff, Abdullatif & Moreland 2012, 89; Katz et al. 2014, 142-150). Parents are able to support the children, build confidence in them and provide a more sustainable effect in comparison to the children receiving guidance alone

(Distelberg et al. 2014, 194–213; Iversen et al. 2018, 2).

An article by Iversen et al (2018) reported that parents usually prefer to receive the guidance because children could get easily distracted and they would not want to raise some pressing issues in the presence of the children (Iversen et al. 2018, 2). However for teenagers (especially age 10-15), the involvement of their parents in guidance could make them feel pressured. Teenagers are usually autonomous and see themselves achieving their Diabetes management, therefore, their view of ability could be opposed to that of their parents' (Ouzouni et al. 2018, 98; Ouzouni, Galli-Tsinopoulou, Kazakos & Lavdaniti 2019, 1299). Some children could conclude that parent involvement in guidance can be out of coercion (Grabill et al. 2010, 281), because parents want to keep the responsibility to themselves and lack confidence in their children (Strand, Brostrom & Haugstvedt 2019, 131).

The factors to consider before guiding are the skills of the parents as well as their health literacy (Deakin 2019, 2). Parents are still responsible for managing the Diabetes of especially young children in their early stage of development, the health literacy of the parent may affect how well they receive guidance (Rechenberg et al. 2016, 120-126).

After the child has been diagnosed with type 1 Diabetes, some family members could have the ability to accept the disease, not live in denial of it and support the child to adhere to guidance (Goldberg & Wiseman 2014,16). On the other hand, some family members could be anxious, fearful and sensitive. Because of this, they could be extremely tolerant, protective or even live in denial of it and limit it in supporting the child (Kadiroglu & Zincir 2018, 172).

The parents of the children could as well be stressed because of the treatment process (Distelberg et al. 2014, 194–213). Because parents want the improvement of their child's adherence to care, they sometimes use words that are perceived as nagging, blaming the children especially adolescents (Moreira, Frontini, Bullinger & Canavarro 2013, 348-355). Parenting stress and relationship between the parent and the child may affect the parent's involvement in guidance which may have an effect on the guidance quality (Nieuwesteeg 2015, 330-336).

The family environment also affects how guidance is received by the child. A positive family environment, not trapped with feudal traditional rules, religious beliefs would give the children right orientation about their disease, while a negative family environment on the other hand that is focused on myths, would limit the child's understanding of the disease (Maslakpak, Anoosheh, Fazlollah & Ebrahim 2010, 464–468; Grimberga, Cousounisa, Cucchiarad, Lipmana & Ginsburgb 2015, 338–348).

7.1.4 Age Specific Issue

Age affects the adherence to care and guidance (McIntosh, Khatchadourian & Amed 2017,225), and could contribute positively in receiving guidance (Viklund & Örtqvist 2014, 77). Age as a factor should be considered in guiding diabetic patients, because it helps to deliver guidance at a level that fits the patient's individual needs (Lašaitė et al. 2016,1500-1503; NCC-WCH 2015, 80-86).

The cognitive and developmental tasks according to the age of the children have an influence on guidance. Toddlers and young children find it difficult to understand their own health problems, explain and describe them clearly. However as they grow older or start school, they are able to understand the caregivers clearly and can now receive guidance from them. (Lohan et al. 2015, 804).

Many young children usually are not mature enough to take the responsibility of caring for themselves, they might end up becoming nonchalant about it. So, it's important for the nurse to get them to participate in the guidance (Sliva et al. 2016, 1594-1597).

As children grow, they have more responsibilities in managing their own Diabetes. Because of this, there's possibility that their family become less involved and reduce support of their management, this may however increase stress for them and affect their adherence to care (Strand et al. 2019,131; Hsin, Greca, Valenzuela, Moine & Delamater 2010, 156-166)

Teenagers usually speak about their issues especially with their peers because their friends provide emotional support for them. This could influence them letting their peers to partake in the guidance. Peer-based guidance proved effective in the management of type 1 Diabetes in teenagers. (Kazemi et al.

2016, 2,10-13)

7.1.5 Gender

Gender is a factor that influences the impact of illness on the patient's wellbeing. Different associations between distress, depression and stress in Diabetes could produce different coping strategies in gender differences. For example, boys are more likely to find it difficult to adjust to Diabetes and may affect their attitude towards guidance. (Lašaitė et al. 2016, 1500-1503).

In an article by Grimberga et al (2015), it was reported that gender has a big impact on medical decision-making during guidance. Parents felt an intervention or some questions asked would be fit for a girl and not a boy and vice-versa (Grimberga et al. 2015, 338–348).

7.1.6 Caring Environment

A safe environment is important for self disclosure in guidance. Set-up of basic directives (such as respecting each other's opinion) is a cornerstone for building a safe-caring environment. Once this is introduced, the hope for receiving guidance and adhering to treatment is raised (Cespedes-Knadle & Munoz 2011, 280). A safe environment helps to improve the nurses competence and helps the patients to become comfortable to receive guidance (Lowes et al. 2015, 14-26).

The article by Livesley and Long (2012) reported that children (younger ones) recognized the environment of the hospital as the most important factor to them and needs to be improved in guidance (Livesley & Long 2012, 1293-1294). A report by Haber, Atti, Gerber and Waseen (2015) suggested that in an interactive session, the participants (parents and children) felt that the emergency department was an appropriate place to receive guidance (Haber, Atti, Gerber & Waseem 2015, 5).

The hospital environment could be a very stressful environment especially for young children, because they are out of their social environment and in a new one. However, playing in the hospital helps them to relieve stress and anxiety since hospitalization detaches children from normal social interaction (Silva et al. 2017, 2295).

Nurse's lack of creation of a supportive environment made the family and the patient frustrated, and this is seen as the main risk factor of fear which hindered acceptance of guidance from the nurse and had a negative influence on guidance quality. A supportive environment is aimed at improving communication and improving knowledge on illness and treatment. (Aftyka et al. 2017, 1013,1018)

Creating an environment that allows training and peer group interaction in guidance by nurses could affect the quality of guidance (Altundag & Bayat 2016, 1013; Silva et al. 2017, 2295; Shepherd 2013, 1037-1039). It assists children with developing their self-perception, improving their self-reliance and mental health conditions (Shepherd 2013,1037-1039).

7.1.7 Attitudes of Nurses

The nurse's attitude to the care has a lot of influences on the quality of the guidance and patient satisfaction. An article reported by Howe, Ayala, Dumser, Buzby & Murphy (2012) mentioned that the nurses' supportive and therapeutic attitude helped in achieving a positive outcome of guidance (Howe, Ayala, Dumser, Buzby & Murphy 2012, 121 - 125). A research carried out by Adereti, Olaogun, Olagunju and Afolabi (2014) in Nigeria reported that the nurse's own behaviour and how he/she treated the patients affected the quality of guidance. For example, several complaints were made that the patients were not treated as individuals, the nurses were not kind to them, and attention wasn't given to them. Some even complained that the nurses did not help them to feel good about themselves. The patients couldn't accept the guidance from the nurses because of the nurses' negative attitude to care. (Adereti, Olaogun, Olagunju & Afolabi 2014, 612-618)

Partnering with the patients is an excellent guidance attitude (Phillips 2016, 333). Nurses gave the patients the chance to express themselves as individuals and not just as patients, gave the children their autonomy and an active role to play in the guidance session (Pelicand et al. 2012, 304-309; Phillips 2016, 333).

An article by Phillips (2016) was reported that the nurse's affective tone at the first meeting gave the patient satisfaction and courage to accept care from the nurse. It was also reported that the nurse was kind and open. The focus of care was also on the patients and not the procedural activity of the hospital. (Phillips

2016, 333)

The nurse created a trust, supportive and comfortable relationship with the patient (Costa et al. 2018, 3279-3286), being interested about the emotional needs (Howe et al. 2012, 121-125), readiness to listen to and empathize with the patients during guidance (Phillips 2016, 333), understanding the children and their family and being interested in them gave a positive influence to the acceptance of guidance (Howe et al. 2012, 121 - 125).

Several articles suggested that the nurse was able to empower patients to make their choice (Bennett 2013, 36,38; Pelicand et al. 2012, 304-309). Another article by Tamayo et al (2013) suggested that the nurse's individual motivation to care affects the quality of guidance (Tamayo et al. 2013. 211).

7.1.8 Patient-Nurse Relationship

A very key factor of guidance is the patient-nurse relationship. Studies stated that forming a close, trusting and effective relationship with the patient is important in guidance and they can overcome barriers to care (Holmström et al. 2018, 116-117). The nurse was able to help her patient who was a child to manage her Diabetes and guide her (Bennett 2013, 36,38).

Nurses who are approachable and communicate actively always find it easier to build a relationship to support the children and their families (Fletcher et al. 2011, 43-44). Positive facial expressions like a smile contributes to a relaxed atmosphere and easy build up of a good nurse - patient therapeutic relationship (Fletcher et al. 2011,43-44). It was reported that an established relationship at the first time of meeting between the nurse and the patient including the parents helped the nurse to earn the patient's trust and made the guidance effective (Bennett 2013, 36,38).

An article by Livesley and Long (2012) reported in a research that children identified relationships with the nurses among other factors as what mattered most to them and what needs to be improved in the hospital and guidance (Livesley & Long 2012, 1293-1294). The patient had comfortability because the nurse was friendly and there was a good relationship between her and the nurse. This helped her to accept guidance from the nurse (Costa et al. 2018, 3279-3286).

A study conducted in one of the authors' home country (Nigeria) by Adereti et al (2014) reported that nurses who were very focused on the procedural activities of the hospital can forget about their patients. Due to the negligence of the nurses, the place of nurse-patient relationship gets reduced and the children and their families become unsatisfied with the care thus affecting the guidance quality (Adereti et al. 2014, 612-618). It was also suggested in the article as supported by Jean Watson's theory that nurse-patient relationship promotes the best professional care. It was reported that the patients were not satisfied with the care because there was no relationship between them and the nurses (Adereti et al. 2014, 612-618).

Lack of cooperation between the nurse and the parent of the child affects clinical decision making. However, a good contact between the nurse and the parent of the child gets the parent comfortable and satisfied, thus giving a positive influence on the outcome of guidance (Aftyka et al. 2017, 1013,1018). Many children and their family get stressed when they're hospitalized, a good nurse-patient relationship is a factor that plays a major role in their acceptance of guidance and care from the nurse (Tavallali et al. 2013, 255-261).

7.1.9 Patient Psychological Health

An article reported that diseases seriously have an influence on the esteem of patients, especially among adolescence (Altundag & Bayat 2016, 1013; Lašaitė et al. 2016, 1500,1503). However, cognitive restructuring, goal setting and other psychological interventions in guidance could alleviate the influences (Islam 2018, 2; Borges, Neto, Falcão, Silva & Freitas 2016, 2332-2333).

After diagnosis, there is a feeling of increased stress, anxiety, depression and even psychosomatic conditions making them feel ashamed which could affect guidance negatively and is even linked to poor behavioural disease management resulting to reduced self-efficacy and self-care (Lašaitė et al. 2016, 1500,1503; Loven 2017, 1-10; Ouzouni et al. 2019, 1299; Borges et al. 2016, 2332-2333; Islam 2018,2).

It is important for nurses to give awareness and attention to the cognitive and behavioral health of the children, especially for adolescents, puberty brings emotional difficulties and changes in their mental condition, life-long disease also

adds extra burden on them (Petersson et al. 2016, 251 - 252; Islam 2018, 2; Maslakpak et al. 2010, 464–468). Giving attention to management alone may likely have an unsuccessful guidance outcome (Hackworth et al. 2013, 360-368). An article by Lowes et al (2014) reported that the children felt more comforted and were able to receive guidance from nurses when their emotional needs were supported, however, it was also suggested that the emotional needs of the parents should be cared for also and not only the children (Lowes et al. 2014, 55-60).

The presence of an underlying mental health condition increases the risk of lack of adherence to treatment, lack of motivation to learn from the nurse or receive guidance from the nurse (McIntosh et al. 2017, 225; Altundag & Bayat 2016, 1013).

7.1.10 Race and Culture

Several studies suggested that race and ethnicity of both the nurses and the patients play a role in effective nursing guidance (Deakin 2019, 2; Rechenberg, et al. 2016, 120-126; Grimberga et al. 2015, 338–348; Valenzuela et al. 2014,1369, 1371-1374; Yafi 2015, 92).

Differences in the belief system of the children and their parents (culture, religion etc) could influence their acceptance of guidance, and this should be considered by the nurses before implementing an intervention (Deakin 2019, 2; Palladino & Helgeson 2013, 176; Valenzuela et al. 2014, 1369,1371-1374; Grimberga et al. 2015, 338–348). For example, an article by Palladino and Helgeson (2013) reported that the mother of a child refused to receive insulin guidance from the nurse because she believed that God will heal her daughter and not the insulin (Palladino & Helgeson 2013, 176). Another article by Cespedes-Knadle and Munoz (2011) also reported that the cultural beliefs of the Latinos is inconsistent with biomedical research (Cespedes-Knadle & Munoz 2011, 280).

Nurses of different races in a country (the minority group), found it difficult to adjust to their new environment of practice. This therefore affected the skills and competences of the nurses to give proper guidance to the patients and meet their needs (Tavallali et al. 2013, 255-261). A study carried out in Norway by Tavallali et al (2013) reported that, because of the culture of most minority

nurses, they tended to be authoritative in their guidance approach, thus the patients got frustrated and it affected guidance negatively. However, in this same study, it was reported that the children and their parents felt and emphasized that the cultural background of the nurses should have no influence on the nursing care. All they were interested about was their nursing skills, medical and professional knowledge as well as the nurses' personal attributes. Some even preferred nurses of different ethnic groups to care for them. (Tavallali et al. 2013, 255-261)

7.1.11 Multiple Knowing

There are some other key factors that could have effects on guidance quality. One of the key factors to consider while giving guidance is the literacy level of the child especially pertaining to health (Deakin 2019, 2). In giving guidance, information is always passed from the nurse to the patient (child), the level of understanding and literacy level of the child could influence the quality of the guidance because the child may or may not understand what the nurse is communicating to her especially if the language is not in his/her level. Information may be overwhelming and the child could lose the information by forgetting them (Bennett 2013, 36,38; NCC-WCH 2015,80-86).

It was reported that the time of the guidance affected the acceptance of guidance from the nurses. Receiving guidance during the diagnosis makes the guidance less effective, this is because the children could get distressed, depressed, and not have patience (Marker et al. 2019, 2,7). A study by Chafe et al (2015) reported that parents felt that the load of information given to a child when the child is first diagnosed is too much because they may not understand the nurses (Chafe et al. 2015, 4-6).

Reading skills and numeracy skills are also important barriers to guidance, for example many calculations are needed while counting insulin dosage or carbohydrate in diet etc (Pulgaron et al. 2014, 67). Studies also suggested that lack of knowledge and motivation to learn influenced the guidance quality. (Tamayo et al. 2013, 211; McIntosh et al. 2017, 225; NCC-WCH 2015,80-86)

7.2 Interview Results

Two kinds of questionnaires were used for the interview: open-ended

questionnaire and closed-ended questionnaire (Appendix 1 and Appendix 4). The open ended question part made sure the participants were able to freely express their opinions about the factors that affect guidance. While the closed ended questions used to help researchers understand the importance of the reviewed factors to our participants. However the results of both questionnaires were based on the theoretical contents derived from the literature review method.

In communication part, participants believe it would be difficult for them to understand the instruction and explanations if medical professionals use complicated medical languages, half of them think if nurses do not speak same language with the patient, it could make understanding to be complicated, and still a few patient believe incongruent verbal and non verbal expressions could be a problem for them to understand nurses' guidance. None of those eleven patients thought nurses should follow their family language. Participants also mentioned the importance of communication as nurses should use words that children would understand while providing guidance and encouraging words should be mentioned to children often.

Most of the participants consider peer group interaction as the most important guidance method for improving the quality of guidance. A small part of the participants ticked that video guidance or video games improve acceptance of guidance. None of the patients chose simulation as a factor that would improve guidance. However, one twelve years old boy mentioned while studying difficult Diabetes skills, such as insulin pumps, it would be better to practice a similar insulin pump in advance before applying it on himself, although he did not pick a simulator as an important factor in the close ended questionnaire. Same participant also mentioned that the guide book would make Diabetes study effective. Another participant pointed out that while patients lack the motivation to change or stick to guidance, motivational meetings could be arranged, and it is an important part to get a patient's attention in Diabetes caring.

Almost all patients agree that family support is an important factor in guidance. Only one participant believed nurses' gender would affect the quality of their guidance and two of them think nurses from different countries would be a factor to affect their guidance.

Children's age is seen as a big influence in receiving guidance, most of the

participants selected children's knowledge, abilities to take care of themselves and puberty related issues as a big problem in caring for their own Diabetes. However, nurses' age is not seen as a factor by patients and their family members as long as nurses can provide good guidance and advice.

Although it was previously stated that patients believed peer group interaction would improve the quality of guidance, participants did not think it would be a big problem if the hospital environment does not provide peer group support. Half of patients believe that the hospital environment and leisure opportunity in the hospital environment are factors which could make the guidance effective. All participants believed that supportive and helpful nurses are key factors to improve guidance. Participants expect nurses to provide clear explanations with all the complicated processes, and nurses are expected to stay calm and be patient to explain the questions that patients came up with, even though those questions have been asked many times.

Nurses' attitudes are seen as the most important factor among all these categories. High percentage of the participants agreed that the nurse's way of talking and nurses' respect for patients' opinions belong to factors that have influence on guidance. Besides these, nurses are friendly and approachable and are selected by all participants. Open and cheerful attitude is mentioned as a positive attitude while providing guidance. One participant pointed out that guidance should involve children in the process, not only their guardians. The patient's own opinion is important and reasonable arguments are supposed to be respected and considered while providing guidance.

Almost all the participants pick the patient-nurses relationship as it has strong influence with guidance. most of the participants were more willing to receive guidance from nurses who have a smile on their face while talking and able to talk actively with them.

A surprising result received from the interview is that only a small group of participants felt stressed or anxious when they first knew they have Diabetes, and they do not consider it as a serious effect on guidance. Quite a little number of the participants think underlying mental or emotional problems would be a problem in receiving guidance, however, they do believe if nurses pay more attention to their emotional condition and provide support for it, it would possibly

improve the quality of guidance.

Participants' opinion on multiple knowing choices are various. Almost no participants think their literacy level would be a hindrance for them to receive guidance. However, most participants believed if patients have motivation to receive guidance, it would be easier for patients to benefit from the guidance. Half of our participants considered the patient's reading skills or calculation skills as an important factor in guidance and the same result shows on the time that nurses provide guidance.

One participant stated that compared to patient skills and knowledge, if nurses would be able to get to know the client’s life situation, rhythms of life, and an overall picture of lifestyles before providing guidance would be a plus for guidance results.

8 THESIS RELIABILITY, VALIDITY AND ETHICAL CONSIDERATIONS

Validity in qualitative research shows accuracy and trustworthiness of a scientific study. This will include the activities and events that are associated with and signified by the results of the study explored in the research. (Golafshani, 2003, 602: Brink, 1996, 36)

Reliability on the other hand shows consistency, stability, and reiteration of a study as well as the researcher's ability to collect and record data accurately. The implication of this could mean that the research method would yield the same results even after testing the research for long periods. (Brink, 1996, 36)

In our thesis work, reliable sources were used as our source of information. This means that the materials used were dependable, and are very scientific. This implies that the credibility, neutrality, consistency and applicability of every material to be used were assessed.

The quality of materials were tested to ensure the validity of the material. This means that, for a material that was used, the material met some criteria like the date of publications, modifications of the article, new findings, credibility, neutrality, consistency and applicability etc. Therefore, this implies that the reliability of the thesis work is based on the validity of the materials to be used. So, in making our thesis work reliable, the materials were valid, trusted.

In this thesis, articles, journals, books and other sources that were used as materials will be referenced properly according to the LUAS guidelines to avoid plagiarism.

Questionnaire (Appendix 1), consent forms and information papers (Appendix 2) were written in English originally, and translated to Finnish (Appendix 3 and Appendix 4) with the help of a translator. Answers received from open ended questionnaires were translated to English to help researchers understand the content. Professional translation was used to ensure content accuracy.

The target group that was used for the interview was voluntary. Some hours before the interview started, participant information sheets and consent forms were given to volunteers. This implies that they were able to understand what is being asked of them, have adequate information of what they are being asked

and can exercise their will power for participation (Siti 2018, 4-5). As vulnerable participants, if young children are not able to give consent independently to participate in research, guardians must be obtained and,in addition, children must not object to participation (Goodman & Moule 2009, 59). In this situation, guardians have the right to help with the research process with the informed consent form.

All the research papers were kept with one researcher, and all the paper after the research were scanned and saved on the computer in order to prevent information loss. Researchers did all interviews under the supervision of Diabetes nurses in Lasi-pohja hospital in order to minimize the anxiety of children with unfamiliar people, and ensure justice in the whole research procedure.

Also, confidentiality and anonymity were put into effect, that is, the participants' identification were preserved by not revealing their names and identity in the data collection, analysis and results of the thesis. Privacy and confidentiality of the interview environment were managed carefully during data analysis and collection of the findings (Siti 2018, 4-5).

9 CONCLUSION

This research is about improving guidance for children with Diabetes type 1. The focus of the thesis was to find out the factors that influence the quality of guidance for children with type 1 Diabetes. When children are first diagnosed with Diabetes, they receive guidance from the nurse to help in their self-management, however, the quality of the guidance could be affected either negatively or positively by some factors.

These factors were deduced from articles and are summarized into 11 factors in our thesis which are: Communication, Guidance methods, Family Influence, age, gender, caring environment, nurses' attitude, patient-nurse relationships, patient's emotional and psychological health, race and cultural beliefs and Multiple knowing.

Communication problems such as language barriers, communication abilities and cognition of the children have an influence on guidance. Both verbal and non-vebal communication have an effect on guidance, congruent communication with children are important and understandable language should be applied in guidance as well as good dialogue.

Different approaches are of great consideration in leading effective guidance. These approaches could be attractive to the children (for example, the use of video games), while some could seem realistic, help to build confidence and make the patients nervous.

The influence of the family in care is another factor that could have influence on guidance. Family support makes children to easily receive and stick on the guidance from health care professionals and provide necessary emotional support, however, while relationships in the family changes, family centered care is easily affected.

Young children generally have problems in understanding the meaning of the disease and receiving guidance independently, this is because of their cognitive and developmental tasks level. However, as they grow, children could gradually take over the responsibility of care from their parents. This could be a contributing factor of the effect of age to guidance.

While building an effective communication, some questions could be fit to ask from boys and not girls and vice versa. A safe and supportive environment has a positive effect on guidance, nurses should be able to create a suitable environment for children during guidance. Kind therapeutic attitude helps patients feel good about themselves, a negative nursing attitude on the other hand will be an hindrance to guidance.

Establishing a good nurse patient therapeutic relationship at the first time of meeting helps nurses to earn the patient's trust and make guidance effective. Nurses who are approachable and communicate actively with positive facial expression find it easy to build up a relationship.

After diagnosis, patients could easily go through shock and followed by several psychological complications, nurses should be aware of these problems and choosing the right time providing guidance could double the result with half the effort.

Race, ethnicity and cultural differences such as traditions, religious beliefs usually have an effect on the guidance quality. Such differences could affect how the nurse gives guidance and how the patients receive them. Understanding the cultural differences could make nurses easily have connection with patients and provide guidance.

Other factors including literacy level for both children and family members, calculation skills and motivation (which are summarized into multiple ways of knowing) are factors to effective guidance.

The authors of this research give high importance to finding the factors that affect guidance and how they can be improved. The authors believe that this research will help nurses to give proper guidance and help the patients how to receive them. However, since the research is a nursing science research which aims to develop knowledge and health promotion, it is more beneficial for the nurses.

Nurses have the responsibility to provide proper guidance for their patients to enable good self-management. It is important for them to put these factors in mind because it could help them to give adequate guidance to the patients. Nurses must understand that good communication is important in guidance and

learn to use words that are not too difficult to understand while guiding their patients. Better methods of guidance should be used adequately while guiding, and respect for involvement or non involvement of family members in guidance as well as opinions of the children should be considered. It is vital for nurses to understand the influence of age, gender and environment in guidance. Respect for the gender, maturity and creation of a safe and supportive environment should be made available in order to overcome such influences that they impose to guidance.

It is paramount that nurses have an attitude of compassion towards their patients as well as create a therapeutic relationship with their patients and not only focus on the procedural activity of the healthcare organization. Checking the psychological state of the patient is also a priority example by asking their emotions in case they do not understand something. Nurses should respect the race, cultural, religious beliefs of their patients. Nurses of different races in a country (the minority group) should adjust to their new environment of practice because it affects their skills and how they give guidance. Also, it is expedient that nurses consider the health literacy of their patients, not give too much information especially in cases of new diagnosis and take note of the time they give guidance because they have influences on the quality of guidance given and adherence by the patients.

10 STRENGTHS AND LIMITATIONS

The strength of this study is based on several factors. First, the purpose and aim of the study was met and the research question was answered. Secondly, multiple articles that fit our research question were used as mentioned in the inclusion criteria, data analysis and collection were described. Thirdly, the chosen articles that were used for the study were relevant on the account that their studies were done around the continents of the world. Lastly, participants of different age groups of our target group were involved in the interview

In our thesis, we have used articles from only three databases: PubMed, CINAHL and JBI. Articles published in other journals or databases were not checked. Only articles written in English or published in English version were reviewed, articles written in other languages were not checked. Only articles which related to keyword ‘pediatric Diabetes’, ‘Diabetes education’, ‘factors influence guidance’ ‘Type 1 Diabetes guidance children’, ‘pediatric Diabetes’, ‘Diabetes’, 'pediatric guidance’, ‘Pediatric education' and ‘pediatric Diabetes education’ were found from database, other related articles which might marked by other keywords were not included. Only recent 10 years articles are reviewed (from 2010-2019), articles published in earlier or later years are not reviewed. All the factors are summarized by authors using a reasonable inductive method from the scientific articles.

Interview was conducted in the polyclinic of one central hospital in Northern Finland. Only 11 people who came to the polyclinic were interviewed. The target group were children aged from 0 - 17 years, participants might have had limited understanding of our research expressions or vocabularies because of their literacy level. Because of the Covid -19 pandemic, researchers were not able to show up in the polyclinic and explain the research paper to the participants and give answers to questions when asked.

11 DISCUSSION AND RECOMMENDATIONS

Adequate guidance and support, especially during the illness phase, are important for the success of self-care in the future because they improve quality of life and prevent acute complications and associated illnesses (Suomalainen Lääkäriseura Duodecimi et al. 2020). However, guidance may or may not be received. This is because there are some factors that may affect the quality and acceptance of guidance either positively or negatively. In this research, 11 major factors were summarized to serve as a mirror for the healthcare professional to help them to access the reasons while children do not adhere to guidance.

Family centered care is the focus of pediatric nursing. Young children who are not able to receive guidance from health-care givers will be supported by family members (Bowden & Greenberg, 2010). However, parents usually prefer to be fully incharge during guidance because they conclude that children are easily distracted (Iversen et al. 2018, 2), from interviews conducted at the hospital, children also want to be fully involved in the guidance, and their reasonable opinions listened to even though they may have limited knowledge about Diabetes and the management. As children get more involved in guidance, they gradually become familiar with and understand Diabetes management hereby reducing the workload of care by their parents.

As stated in studies used for literature review, communicating incongruently may be incomprehensible for patients. However, from the interviews conducted at the hospital, many of the participants of our study did not see incongruent communication as a factor that would affect their adherence to guidance. They were satisfied as long as nurses were patient with them, even patients asked the same questions repeatedly. Nurses are supposed to avoid using difficult medical words and nurses are able to answer their questions with understandable language.

Technological developments provide opportunities for medical services e.g. make patients' treatment to be safe and guidance easier. For example, insulin simulators, video games, carbohydrate calculation apps or VR simulation environments are good technological devices that can be used as methods for guidance. However, the participants of our study did not consider them to have an effect on guidance, they felt trust, interpersonal relationships and having

motivational interviews or using peer support groups are of more relevance. As researchers of this study, we do not play down on the effects of any of these guidance methods.

Although the participants of our interview did not see cultural background and religious difference as factors while research articles stated otherwise, from our point of view, the authors of this study believe that difference in cultural background may make it difficult for nurses to understand the patient's life situation, way of expression and social status. Based on our experiences, we believe that nurses who are foreigners may find it difficult to adjust to the new environment and this may affect their skills to meet the needs of their patient. (Tavallali et al. 2013, 255-259)

In this thesis, some factors like nurses' attitude or communication were highlighted in both methods of research used. However, some of the other factors do not seem to have a huge affect on guidance individually. Nevertheless, one factor could lead to another factor, a new problem or combined risks which could influence the guidance process.

This research has a good receptivity by the supervisor, commissioner, and the participants of the interview method. A multimethod which consists of descriptive literature review and interview to get a qualitative result was used.

Initially, we thought this thesis would be difficult because it was a lot of work that involved a lot of time and energy. Also, looking at the context of the research, it could be very easy to go out of the context of the aim, purpose and research question of the thesis focusing on the disease (Type 1 Diabetes) and not ' factors that affect the quality of guidance'. However, we were able to stay in the context of our research. The literature review took us about a month to analyze.

Another challenge was the coronavirus pandemic. Because of the pandemic, the polyclinic of the hospital was closed, and we could not have our interview, hence the target of completion of the work couldn't be met. However fortunately for us, the polyclinic was eventually opened. Through the help of the polyclinic nurse (who is the commissioner of this thesis), we had our interview using both open and closed questionnaires. These questions were officially translated and sent to the hospital for the interview since our target group speaks Finnish language.

The results of this research helped us to see nursing on both the patients' (including their family members) and nurses' points of view clearing bias mindset.

In addition to this work, the authors of this thesis would suggest for Lapland University of Applied Sciences to make awareness of the results of this thesis and likewise the Central Hospital because it is useful for the nurses.

Furthermore, since there has been no research done regarding this topic in Lapland and in Finland, we recommend that further research be made regarding this topic. It is also recommended that these further researches be conducted in Finnish language since our result was conducted in English language, and these further researches could yield a quantitative result.

BIBLIOGRAPHY:

Adams,M.P. & Holland, N. 2011. Pharmacology for nurses:A Pathophysiologic Approach, 3rd Edition. 678-683.

Allison,M. & Chaar, B. 2016. How to build and maintain trust with patients. The Pharmaceutical Journal. Accessed 31st May,2020. https://www.pharmaceutical-journal.com/eye-care/how-to-build-and-maintain-trust-with-patients/20201862.article?firstPass=false

Angelo, G. 2016. Jean Watson Theory: Theory of Human Caring. Accessed 7th Jan. 2020. https://nurseslabs.com/jean-watsons-philosophy-theory-transpersonal-caring/

Anne-Louise, B. Febe, F. Eva,P. & Elisabeth, D. 2015. 'Registered Nurses' Patient Education in Everyday Primary Care Practice Managers' Discourses'. Vol.2, 1 - 5.

Anthony, M. Cognitive Development in 0-2 Year Olds. Scholastic. Accessed 21st July 2020. https://www.scholastic.com/parents/family-life/creativity-and-critical-thinking/development-milestones/cognitive-development-0-2-year-olds.html

Australia National Health and Medical Research Council. 2016. Eating Well. Accessed 1st June, 2020. https://www.eatforhealth.gov.au/eating-well

Bakari,S. & Doreen,N. 2016. Good Quality Interaction between The Registered Nurse and The Patient. Seinajoki University of Applied Sciences. Faculty of Social work and Healthcare, Bachelor's thesis.

Bird, S.R. & Hawley, A.J. 2017. Update on the effects of physical activity on insulin sensitivity in humans. BMJ Open Sport & Exercise Medicine. Vol 2, No.123,1-26. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5569266/pdf/bmjsem-2016-00043.pdf

Bloch,C.A. Clemons,P. & Sperling,M.A. 1987. Puberty decreases insulin sensitivity. National Library of Medicine. Vol.110,No 3. Accessed 21st July 2020. https://www.ncbi.nlm.nih.gov/pubmed/2950219

Borges,B.V.S., Neto, J.C.G., Falcão,L.M., Silva, A.P. & Freitas, R.W.J.F. 2016. Type 1 Diabetes Mellitus in Adolescents: From Diagnosis to the daily contact with the illness. Journal of Nursing UFPE On Line. Vol.10. No.7. 2332-2333.

Brink, H.I.L.1993. Validity and reliability in qualitative research. Research Gate. Vol. 16, No. 2. 35-38. https://www.researchgate.net/publication/14824314_Validity_and_reliability_in_qualitative_research

Centers for Disease and Control. 2020. Type 1 Diabetes. Accessed 31st March, 2020. https://www.cdc.gov/Diabetes/basics/type1.html

Coulter, A. & Ellins, J. 2007. Effectiveness of Strategies for informing, educating

and involving patients. British Medical Journal Vol 335, No 7609, 24-27. https://www.researchgate.net/publication/6223140_Effectiveness_of_strategies_for_informing_educating_and_involving_patients

Diabetes: Role of Family Involvement and Acculturation. Journal of Pediatric Psychology. Vol.35, No.2. 156-166.

Durgun,Y., Okumuş,H. & Lash,A. 2015. 'Implementation of Watson's Theory of Human Caring: A Case Study'. International Journal of Caring Sciences. Vol. 8. No 1, 25 - 27. https://www.internationaljournalofcaringsciences.org/docs/4-Lash%20-%20Original.pdf

Edelman, C.L., Elizabeth, C.K. & Mandle, C.L. 2014. Health promotion throughout the lifespan 8th edition. Elsevier Mosby. 1468-1530.

Elo, S., Kääriäinen,M., Kanste,O., Pölkki,T., Utriainen,K. & Kyngäs,H. 2014. Qualitative Content Analysis: A Focus on Trustworthiness. Sage Open.1-10. https://journals.sagepub.com/doi/pdf/10.1177/2158244014522633

Elo, S. & Kyngäs, H. 2008. The qualitative content analysis. Journal of Advanced Nursing. Vol.62, No.1. 107-115. https://www.researchgate.net/publication/5499399_The_qualitative_content_a

Erkkilä,M. 2019. Anxiety in first-time birthing mothers. A Systematic Literature Review. Lapland University of Applied Sciences, School of Health Care and Social Services. Degree Programme in Nursing. Bachelor's Thesis. 19-24. https://www.theseus.fi/bitstream/handle/10024/185121/Bachelor%27s%20thesis_Maija_Erkkila%cc%88.pdf?sequence=2&isAllowed=analysis

Finnish Diabetes Association.2019. One out of ten has Diabetes. Assessed 15th Jan. 2020. https://www.Diabetes.fi/en/finnish_Diabetes_association/Diabetes_in_finland

Garg, Rakesh. "Methodology for research I." Indian journal of anaesthesia 2016. Vol. 60. No 9, 640-645. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5037944/

Gaur,A. & Kumar,M. A systematic approach to conducting review studies: An assessment of content analysis in 25 years of IB research. Journal of World Business, forthcoming. 2017, 6-8. https://ajaigaur.files.wordpress.com/2017/09/content-analysis-in-ib-gaur-mukesh-jwb-2018.pdf

Ghimire, P. & Dhamoon, A.S. 2020. Ketoacidosis. Statpearls publishing. Accessed 3rd April, 2020. https://www.ncbi.nlm.nih.gov/books/NBK534848/

Gill,P., Stewart,K., Treasure,R. & Chadwick,B. 2008.'Methods of data collection in qualitative research: interviews and focus groups 'British Dental Journal Vol. 204. 291–295. https://www.nature.com/articles/bdj.2008.192

Glyn, E.,Christine, D., Ronald, M.E., Katty, M., James, W. & Dominick, L.F. 2014. Shared Decision Making and Motivational Interviewing: Achieving Golafshani, N.

2003. Understanding Reliability and Validity in Qualitative Research. CORE. Vol.8,No.4. 597-607. https://core.ac.uk/download/pdf/51087041.pdf

Goodman, M. & Moule, P. Nursing research an introduction.Sage publications. 2009. 51-70, 349-351.

Gurm, B. 2013. Multiple Ways of Knowing in Teaching and Learning. International Journal for the Scholarship of Teaching and Learning. Vol. 7, No. 1. 2-6. https://digitalcommons.georgiasouthern.edu/cgi/viewcontent.cgi?article=1365&context=ij-sotl

Jarva, S. & Haavisto, M. 2018. Developing Trust in a Nurse-Patient Relationship A Literature Review. JAMK University of Applied Sciences, Social Services and Health Care Degree Programme in Nursing. Bachelor's Thesis. 3 - 5. https://pdfs.semanticscholar.org/72eb/73c8076b086413400d1477a3dacccd73f662.pdf

Jyväskylän yliopisto. 2010. Multi-method Research. Accessed 1st June,2020. https://koppa.jyu.fi/avoimet/hum/menetelmapolkuja/en/methodmap/strategies/multimethod-research

Kahanovitz,L., Sluss,P.M. & Russell, S.R. 2017. Type 1 Diabetes – A Clinical Perspective. Point Care. Vol.16, No.1. 37–40. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5606981/pdf/nihms842436.pdf

Kuhlthau,A.K., Bloom,S., Vancleave,J., Knapp,A.A., Romm,D., Klatka,K., Homer,C.J., Newacheck,P.W. & Perrin,J.M. 2011. 'Evidence for family-centred care for children with special health care needs; A Systematic Review'. 2011, 136 - 140

Kuusisto,M., Lipponen, J.,Kähkönen, J.,Määttä, H.,Jahangiri, R., Hämäläinen, J.,Räisänen, A., Vähäsarja, M., Alaraudanjoki, E.,Paarma, K., Saviaro, N.,& Kovalainen, E. 2020. Diabetes 1. Skhole. Assessed by August 28th 2020. https://app.skhole.fi/en-US/courses/internal-medicine/lessons/Diabetes-1-2

Kuo,D.Z., Houtrow,J.A., Arango,P., Kuhlthau,K.A., Simmons,J.M. & Neff,J.M. 2012. Family Centred Care: Current Applications and Future Directions in Pediatric Health Care. Maternal Child Health Journal. Vol 16. 297 - 305.

Maarten, D.W. Cyrus, C. & Jean-Yves, R. 2019. Practical Guidance for Patient-centred Health Research. The Lancet. Vol 393, no 10176, 1095 & 1096. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(19)30034-0/fulltext

Markowitz, J.T., Garvey, C.K. & Laffel, L.M.B. 2015. Developmental Changes in the Roles of Patients and Families in Type 1 Diabetes Management. Current Diabetes Reviews. Vol 11, No 4. 231-238. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4826732/

Marja, N. & Klas W. Diabetes in Finland: Prevalence and Variation in Quality of Care. Finnish Diabetes Association STAKES – National Research and Development Centre for Welfare and Health 2006, 5&9. Accessed 3rd March, 2020.

https://www.Diabetes.fi/files/1105/Diabetes_in_Finland._Prevalence_and_Variation_in_Quality_of_Care.pdf

National Institute for Health and Welfare. 2015: 'Prevalence of Diabetes' Accessed 3rd March, 2020. https://thl.fi/fi/web/kansantaudit/Diabetes/diabeteksen-yleisyys

New York State Office of Children and Family Services 2015. Child Development Guide: Center for Development of Human Sciences. 35 - 55. https://ocfs.ny.gov/main/fostercare/assets/ChildDevelGuide.pdf

NHS Estates. Improving the Patient Experience: Friendly environments for children and young people.2004. 40-50. http://www.wales.nhs.uk/sites3/Documents/254/FriendKids.pdf

NHS UK. 2018. Type 1 Diabete; Avoiding Complications. Accessed 22nd April, 2020. https://www.nhs.uk/conditions/type-1-Diabetes/avoiding-complications/

Nicole,D.W. 2017 Alcohol Use in Young Adults With Type 1 Diabetes Mellitus. American Journal of Lifestyle Medicine, Vol 11. No.6, 433-435. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6125008/pdf/10.1177_1559827617722137.pdf

Özyazıcıoğlu, N., Avdal, E. Ü.& Sağlam, H.2017. A determination of the quality of life of children and adolescents with type 1 Diabetes and their parents. Science Direct. Vol.4, No.2.94-98. https://www.sciencedirect.com/science/article/pii/S2352013216301612

Patient-Centered Care Across the Spectrum of Health Care Problems. Annals of Family Medicine. 270-275. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4018376/pdf/0120270.pdf

Pettoello-Mantovan, M., Campanozzi, A., Mauiri, L. & Giardino, I. 2009 Family-oriented and family-centered care in pediatrics. Italian Journal of Paediatrics. Vol 35, No 12. 1-8. https://ijponline.biomedcentral.com/articles/10.1186/1824-7288-35-12

Pirjo, I.P 2018. Tyypin 1 diabeteksen hoito; Lääkärikirja Duodecim. Accessed 10th March, 2020. https://www.terveyskirjasto.fi/terveyskirjasto/tk.koti?p_artikkeli=dlk00774

Hakkaraine, H., Sund, R., Arffman, R.,Koski,S., Hänninen, V., Moilanen, L. & Räsänen, K. 2017. Working people with type 1 Diabetes in the Finnish population. Assessed 7th Jan 2020. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5639775/

Räsänen, S.& Niemelä, M. 2012. Families experiences of Diabetes guidance in Pediatric ward 1. Jamk University of Applied Sciences, Degree Programme in Nursing Social services, Health and Sport. Bachelor's Thesis, 2-20. https://www.theseus.fi/bitstream/handle/10024/56893/Rasanen_Sanni.pdf?sequence=1&isAllowed=y

Rechenberg,K., Whittemore,R., Grey,M., Jaser,S. & TeenCOPE Research Group. 2016. Contribution of income to self-management and health outcomes in

pediatric type 1 Diabetes. Pediatric Diabetes.Vol.17.No.2. 120-126

Ruxer,J., Mozdzan, M., Czupryniak,L., & Loba,J. 2003. Long-Term Discontinuation of Insulin Treatment in a Type 1 Diabetic Patient. Diabetes Care. Vol. 26, No.4. https://care.Diabetesjournals.org/content/26/4/1314

Scott, J.A. 2011. Stress and Type 1 Diabetes. Everydayhealth. Assessed by 7th September 2020. https://www.everydayhealth.com/type-1-Diabetes/stress-and-type-1-Diabetes.aspx

Sfandyarifard, E.Sutrisna, M. & Tzortzopoulos, P. 2010. Meeting user's needs : children and young people in hospital environment. School of the Built Environment, University of Salford. 96. https://www.irbnet.de/daten/iconda/CIB18842.pdf

Shields, L., Pratt, J. & Hunter, J. 2006. Family Centred Care: A Review of Qualitative Studies. Journal of Clinical Nursing. Vol 15, no 10 1317 - 1323

Siti, R. Ethical Considerations in Qualitative Study. International Journal of Care Scholars. 2018, 3-5. https://www.researchgate.net/publication/328019725_Ethical_Considerations_in Qualitative_Study

Snyder, H. 2019. Literature review as a research methodology: An overview and guidelines. Journal of Business Research. Vol. 104. 333-339. https://www.sciencedirect.com/science/article/pii/S0148296319304564

Suomalainen Lääkäriseura Duodecimi, Suomen Sisätautilääkärien yhdistyksen ja Diabetesliiton Lääkärineuvoston asettama työryhmä. 2020. Käypä hoito -suositus. Accessed 1st June, 2020. https://www.kaypahoito.fi/hoi50116#s15

Susan, W. 2013. Pediatric Nursing : Best Evidence-Based Practices. F. A. Davis Company. 7.

The Global Diabetes Community. 2019. Treatment for Type 1 Diabetes. Assessed 31st March, 2020. https://www.Diabetes.co.uk/treatment-for-type1-Diabetes.html

Bowden, V. R. & Greenberg, C.S. 2010. Children and Their Families: The Continuum of Care 2nd edition. Wolters Kluwer Health. 6-9. https://books.google.fi/books?id=JRGl9AxmfHEC&pg=PA6&dq=family+centered+care&hl=en&sa=X&ved=0ahUKEwiHpraK_oXnAhUnyaYKHbDRAv8Q6AEIUzAF#v=onepage&q=family%20centered%20care&f=false

Watson, J. 2008.Core Concepts of Jean Watson's Theory of Human Caring/ Unitary Caring Science. Watson Caring Science Institute. 1-7. https://www.watsoncaringscience.org/files/PDF/watsons-theory-of-human-caring-core-concepts-and-evolution-to-caritas-processes-handout.pdf

Wei, H., Sewell,K.A.,Woody, G. & Rose, M. A.2018. 'The state of the science of nurse work environments in the United States: A systematic review'. International Journal of Nursing Sciences. Vol 5. 290.

https://www.sciencedirect.com/science/article/pii/S2352013218300309#!

White, N.D.2017. Alcohol Use in Young Adults With Type 1 Diabetes Mellitus. American Journal of Lifestyle Medicine. Vol. 11. No. 6. 433-435. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6125008/pdf/10.1177_1559827617722137.pdf

Wit,D. M., Cooper, C. & Reginster, J. 2019. Practical guidance for patient-centred health research. The Lancet Journals vol 393, no 10176, 1095-1096. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(19)30034-0/fulltext

Yang, H.B.& Tate, M. 2012. A Descriptive Literature Review and Classification of Cloud Computing Research. Communications of the Association for Information Systems. Vol.31, No.2. 35-60. https://aisel.aisnet.org/cgi/viewcontent.cgi?article=3672&context=cais

Young-Hyman, D.,Groot, M.D., Hill-Briggs F, Gonzalez JS, Hood K. & Peyrot, M. 2016. Psychosocial Care for People With Diabetes: A Position Statement of the American Diabetes Association. Diabetes Care Journal. 2016. Vol. 39, No.12. 2126-2140. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5127231/

BIBLIOGRAPHY FOR LITERATURE REVIEW:

Adams,J. 2012. Life Experience for an Adolescent with Type 1 Diabetes: Nursing Strategies to Support a Healthy Lifestyle. Whitireia Nursing Journal, issue 19. 18-25.

Adereti,S.C., Olaogun,A.A., Olagunju,E.O.& Afolabi, K.E. 2014. Paediatric Patients and Primary Caregivers' Perception of Nurse-Caring Behaviour in South Western Nigeria. International Journal of Caring Sciences. Vol 7, No.2. 612-618.

Aftyka, A., Rozalska-Walaszek, I.,Wrobel, A., Bednarek, A., Dazbek,K.& Zarzycka, D. 2017.Support provided by nurses to parents of hospitalized children – cultural adaptation and validation of Nurse Parent Support Tool and initial research results. Scandinavian Journal of Caring Science. Vol.31. 1013&1018.

Altundag, S. & Bayat, M. 2016. Peer interaction and group education for adaptation to disease in adolescents with Type 1 Diabetes mellitus. Pakistan Journal of Medical Sciences. Vol.32, No. 4. 1010-1014. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5017069/pdf/PJMS-32-1010.pdf

Bennett, S. 2013. Helping a teenager manage Diabetes. Kai Tiaki Nursing New Zealand. Vol. 19,No.3. 36,38.

Cespedes-Knadle,M.Y. & Munoz, C.E. 2011. Development of a Group Intervention for Teens With Type 1 Diabetes. THE JOURNAL FOR SPECIALISTS IN GROUP WORK, Vol. 36 No. 4, 2011. 280-289

Chafe,R., Albrechtsons,D., Hagerty,D. & Newhook,L.A. 2015. Reducing episodes of diabetic ketoacidosis within a youth population: a focus group study with patients and families. BioMed Central Research Notes. Assessed by 5th June 2020. https://www.researchgate.net/publication/281489586_Reducing_episodes_of_diabetic_ketoacidosis_within_a_youth_population_A_focus_group_study_with_patients_and_families

Chisholm, V., Atkinson, L. ,Bayrami,L.,Noyes,K.,Payne, A. & Kelnar C. 2012. An exploratory study of positive and incongruent communication in young children with type 1 Diabetes and their mothers. Wiley online library: Child: care, health and development. Vol.40, No.1. 86- 87

Christie,D.,Thompson,R.,Sawtell,M.,Allen,E.,Cairns,J.,Smith,F., Jamieson, E., Hargreaves,K., Ingold,A.,Brooks,L., Wiggins,M., Oliver,S., Jones,R., Elbourne,D., Santos,A., Wong,I.C.K., O'Neil, S., Strange,V., Hindmarsh,P., Annan,F. & Viner,R.M. 2016. Effectiveness of a structured educational intervention using psychological delivery methods in children and adolescents with poorly controlled type 1 Diabetes: a cluster-randomized controlled trial of the CASCADE intervention. BMJ Open Diabetes Research and Care. Vol.4. 2-10.

Costa,A.R., Nobre,C.M.G., Gomes,G.C., Rosa, G.S.M., Nornberg, P.K.O.& Medeiros.,S.P. 2018. Perception of the family in a pediatric unit about nursing care. Journal of Nursing. Vol.12 No.12. 3279-3286.

Deakin,L. 2019. Children with Fever: Parent Education. The Joanna Briggs Institute Evidence Based Practice Database. JBI 4089. 2.

Distelberg, B.,Williams-Reade, J.,Tapanes, D., Montgomery, S.& Pandit,M. 2014. Evaluation of a Family Systems Intervention for Managing Pediatric Chronic Illness: Mastering Each New Direction (MEND). Family Process. Vol.53, NO.2. 194-231.

Fletcher,T.,Glasper,A.,Prudhoe,G.,Battrick,C.,Coles,L.,Weaver,K.&Ireland,L. 2011. Building the future: children's views on nurses and hospital care. British Journal of Nursing, Vol 20, No.1. 43-44.

Goldberg,A. & Wiseman,H. 2014. Parents' Sense of Coherence and the Adolescent's Health and Emotional and Behavioral Adjustment: The Case of Adolescents With Diabetes. Journal of Pediatric Nursing. Vol 29. No.16.

Grabill,K.M., Geffken, G.R., Duke,D., Lewin,A., Williams,L., Storch,E. & Silverstein, J. 2010. Family Functioning and Adherence in Youth With Type 1 Diabetes: A Latent Growth Model of Glycemic Control. Routledge Taylor& Francis Group. DOI: 10.1080/02739615.2010.515930. 281.

Grimberga,A., Cousounisa,P., Cucchiarad,A.J., Lipmana,T.H. & Ginsburgb, K.R. 2015. Parental Concerns Influencing Decisions to Seek Medical Care for a Child's Short Stature. Hormone Research in Paediatrics. Vol.84,No.5. 338–348.

Haber, J.J., Atti, S., Gerber, L.M. & Waseem, M.2015. Promoting an obesity education program among minority patients in a single urban pediatric Emergency Department (ED). International Journal of Emergency Medicine. Vol.8, No.38. 5.

Hackworth,N.J., Hamilton,V.E., Moore,S.M., Northam,E.A., Bucalo,Z. & Cameron, F.G. 2013.Predictors of Diabetes Self-care, Metabolic Control, and Mental Health in Youth with Type 1 Diabetes. The Australian Psychological Society. Vol.48. 360-368.

Hilliard M.E., Monaghan M., Cogen F.R., & Streisand R. 2011. Parent stress and child behaviour among young children with type 1 Diabetes. Child: Care, Health and Development, Vol.37,No.2. 224–232.

Holmström,M.R., Häggström,M.& Söderberg,S.2018. Being Facilitators in a Challenging Context-School Personnel's Experiences of Caring for Youth with Diabetes. Journal of Pediatric Nursing. Type 1. Vol.43.116-117.

Howe, C. J., Ayala,J., Dumser, S., Buzby, M. & Murphy,K. 2012. Parental Expectations in the Care of Their Children and Adolescents With Diabetes. Journal of Pediatric Nursing. Vol. 27. 121-125.

Hsin,O., Greca,A.M.L., Valenzuela, J., Moine,C.T. & Delamater,A. 2010. Adherence and Glycemic Control among Hispanic Youth with Type 1 Diabetes: Role of Family Involvement and Acculturation. Journal of Pediatric Psychology. Vol.35. No.6. 156-166.

Islam,S. 2018. Diabetes Management : Considerations for Adolescents. The Joanna Briggs Institute EBP Database, JBI634. 2.

Iversen, H.H., Helland, Y., Bjertnaes, O.& Skrivarhaug, T. 2018.Parent experiences of Diabetes care questionnaire (PEQ-DC): reliability and validity following a national survey in Norway. BMC Health Services Research. Vol.18, No.774. 2.

Katz, M.L.,Volkening,L.K.,Butler,D.A., Anderson,B.J.& Laffel,L.M. 2014. Family-based Psychoeducation and Care Ambassador Intervention to Improve Glycemic Control in Youth with Type 1 Diabetes: A Randomized Trial. Journal of Pediatric Diabetes.Vol.15,No.2. 142-150.

Kadiroglu,T. & Zincir, H.2018. Effect of Family Life and Child Rearing Attitudes on Metabolic Control of Adolescents with Type 1 Diabetes Mellitus. International Journal of Caring Sciences. Vol. 11, No.1. 172.

Kazemi, S.,Parvizy, S., Atlasi, R.& Baradaran, H.R. 2016. Evaluating the effectiveness of peer-based intervention in managing type I Diabetes mellitus among children and adolescents: A systematic review. Medical Journal of the Islamic Republic of Iran. ISSN: 1016-1430. 2,10-13.

Lašaitė,L., Dobrovolskienė,R., Danytė,E., Stankutė,I., Ražanskaitė-Virbickienė, D., Schwitzgebel,V., Marčiulionytė,D. & Verkauskienė, R. 2016. Diabetes distress in males and females with type 1 Diabetes in adolescence and emerging adulthood.Journal of Diabetes and Its Complications. Vol.30. 1500&1503.

Livesley, J. & Long, T. 2012. Children's experiences as hospital in-patients: Voice, competence and work. Messages for nursing from a critical ethnographic study. International Journal of Nursing Studies. Vol. 50, Issue 10. 1293-129

Lohan,A., Morawska,A.& Mitchell,A.2015. A systematic review of parenting interventions for parents of children with type 1 Diabetes. John Wiley & Sons Ltd. Vol41, No.6. 804.

Loven, I. 2017. Labor market consequences of growing up with a sibling with type 1 Diabetes. Social Science & Medicine. Vol.178, No.2017. 1-10.

Lowes,L.,Eddy, D.,Channo, S.,McNamara,R., Robling,M.& Gregory, J.W. 2014. The Experience of Living with Type 1 Diabetes and Attending Clinic from the Perception of Children,Adolescents and Carers: Analysis of Qualitative Data from the DEPICTED Study. Journal of Pediatric Nursing. Vol. 30, Issue 1, 55-60.

Marker, A.M.,Monzon, A.D., Goggin,K.J., Clements, M.A. & Patton, S.R. 2019. Iterative development of a web-based intervention for families of young children with type 1 Diabetes: DIPPer Academy. HHS Public Access. Vol.7 No.1. 2,7.

Marcellus, L., MacKinnon,K., Rivers, J.,Gordon, C., Ryan,M.,& Butcher, D. 2015. Student and educator experiences of maternal-child simulation-based learning: a systematic review of qualitative evidence protocol. JBI Database of Systematic Reviews & Implementation Reports. Vol.13, No.1., 14-26.

Maslakpak,M.H., Anoosheh,M.Fazlollah,A.&Ebrahim,H.2010. Iranian diabetic adolescent girls' quality of life: perspectives on barriers. Scandinavian Journal of Caring Science. Vol 24. 464–468.

McIntosh,B., Khatchadourian,K.& Amed, S.Z.2017. British Columbian Healthcare Providers' Perspectives on Facilitators and Barriers to Adhering to Pediatric Diabetes Treatment Guidelines. Canadian Journal of Diabetes. Vol.41. 225.

Moreira,H.,Frontini,R.,Bullinger,M.&Canavarro,M.C. 2013. Family Cohesion and Health-Related Quality of Life of Children with Type 1 Diabetes: The Mediating Role of Parental Adjustment. Journal of Child and Family studies. Vol.23. 348-355.

Morrison,S.,Dashiff,C., Abdullatif,H. & Moreland,E. 2012.Parental Separation Anxiety and Diabetes Self-Management of Older Adolescents: A Pilot Study. Pediatric Nursing. Vol 38. No.2. 89.

Mulvaney, S.A.,Rothman R.L., Osborn, C.Y., Lybarger,C., Dietrich,M. S. & Wallston, K.A. 2011. Self-management problem solving for adolescents with type 1 Diabetes: Intervention processes associated with an Internet program. Patient Education and Counseling.Vol.85. 140-142.

Naughton,M.J., Yi-Frazier,J.P., Morgan,T.M., Seid,M., Lawrence, J.M. Klingensmith,G.J., Waitzfelder,B., Standiford,D.A.,& Loots,B. 2014. Longitudinal Associations between Sex, Diabetes Self-Care, and Health-Related Quality of Life Among Youth with Type 1 or Type 2 Diabetes Mellitus. Journal of Pediatric. Vol.164, No.6. 1376-1383.

NCC-WCH(National Collaborating Centre for Women's and Children's Health). 2015. Diabetes (type 1 and type 2) in children and young people: diagnosis and management. 80-86.

Nguyen, P. 2016. Type 1 Diabetes Mellitus: Patient Education. Evidence Summary. Type 1 Diabetes Mellitus: Patient Education. The Joanna Briggs Institute EBP Database, JBI@Ovid. 1-2.

Nieuwesteeg,A.M.,Hartman,E.E.,Aanstoot,H.J.,Bakel, H.J.A., Emons,W. H.M., Mil,E. & Pouwer,F. 2015. The relationship between parenting stress and parent–child interaction with health outcomes in the youngest patients with type 1 Diabetes (0–7 years). European Journal of Pediatrics.Vol.2016,No.175. DOI 10.1007/s00431-015-2631-4. 330-336.

Ouzouni,A., Galli-Tsinopoulou,A., Kazakos,K., Dimopoulos,E., Kleisarchaki, A. N., Mouzaki,K.& Lavdaniti, M. 2018. The Intervention of Parents in Supporting of Diabetes Type 1 in Adolescents. Mater Sociomed.Vol.30. No.2.98-102.

Ouzouni,A., Galli-Tsinopoulou,A., Kazakos,K. & Lavdaniti,M. 2019. Adolescents with Diabetes Type 1: Psychological and Behavioral Problems and Compliance with Treatment. International Journal of Caring Sciences. Vol.12, No.2. 1299.

Palladino, D.K.& Helgeson,V.S.2013. Adolescents, Parents and Physicians: A Comparison of Perspectives on Type 1 Diabetes Self-Care. Canadian Journal of Diabetes. Vol.37.176.

Pelicand,J.,Fournier, C.,Rhun, A.M. & Aujoulat, I. 2012. Self-care support in paediatric patients with type 1 Diabetes: bridging the gap between patient education and health promotion? A review. Blackwell Publishing Ltd. 304-309.

Petersson, C.,Huus, K.,Enskär, K., Hanberger,L., Samulesson,U.,& Åkesson, K. 2016. Impact of Type 1 Diabetes on Health-Related Quality of Life Among 8–18-Year-Old Children. COMPREHENSIVE CHILD AND ADOLESCENT NURSING. Vol. 39, No. 4, 245–255.

Phillips, A. 2016. Supporting patients with type 1 Diabetes. British Journal of Nursing. Vol.25, No.6. 333.

Pulgaron, E.R., Sanders, L.M.,Patin o-Fernandez, A.M., Wile,D., Sanchez, J., Rothman, R.L.& Delamater,A.M. 2014. Science Direct. Vol.94. 67.

Ramchandania,N., Maguireb,L.L., Sterna,K.,Quintosc,J.B., Lee, M. & Sullivan-Bolyaia, S. 2016. PETS-D (parents education through simulation-Diabetes): Parents' qualitative results. Patient Education and Counselling. Vol.99. 1362-1367.

Rechenberg,K., Whittemore,R., Grey,M., Jaser,S. & TeenCOPE Research Group. 2016. Contribution of income to self-management and health outcomes in pediatric type 1 Diabetes. Pediatric Diabetes.Vol.17.No.2. 120-126

Reichert,A.P.S.,Rodrigues,P.F.,Cruz,T.M.A.V., Dias,T.K.C., Tacla,M.T. G.M., &Collet,N. 2017. Mothers´ perception about the relationship with nurses in the child consultation. Journal of Nursing. ISSN:1981-8963. DOI:10.5205.485-487.

Shepherd, J.M. 2013. Younger children's nursing students are uniquely placed to provide emotional care for young people in hospital and promote for them a sense of normalcy. Nurse Education Today 34(2014). 1034-1039.

Sliva, A.N.S., Pennafort,V.P.S. & Queiroz, M.V.O. 2016. Sociocultural features and children clinics with type 1 Diabetes: Subsidies to nursing care. Journal of Nursing. ISSN: 1981-8963. DOI: 10.5205. 1594-1597.

Silva,L.S.R., Correia, N.S., Cordeiro, E.L.,Silva, T.T., Costa, L.T.O. & Maia, P.C.V.S. 2017. Nursing Angels: The Playfulness As An Instrument Of Citizenship And Humanization In Health. Journal of Nursing UFPE On line. Vol.11, No.6. 2295.

Strand,M., Brostrom,A.& Haugstvedt, A. 2019. Adolescents' perceptions of the transition process from parental management to self-management of type 1 Diabetes. Scandinavian Journal of Caring Science. Vol.33. 131.

Sullivan-Bolyai,S.,Crawford, S.,Johnson,K.,Huston, B.& Lee, M.M. 2012. Educating Diabetes camp counselors with a human patient simulator: A pilot study. Journal for specialists in pediatric nursing.Vol.17. No.2.121-128.

Tamayo, T., Rosenbauer, J., Wild, S.H., Spijkerman, A.M.W., Baan, C., Forouhi,N.G., Herder, C. & Rathmann,W. 2013. Diabetes in Europe: An update. Diabetes Research and Clinical Practice. Vol.103, No.2. 211.

Tavallali, A.G., Kabitr, Z.N. & Jirwe,M. 2013. Ethnic Swedish Parents' experiences of minority ethnic nurses' cultural competence in Swedish paediatric care. Scandinavian Journal of Caring Science. Vol.28. 255–263.

Valenzuela, J.M., Seid, M.,Waitzfelder, B.,Anderson, A.M.,Beavers, D.P. ,

Dabelea, D.M., Dolan, L. M., Imperatore, G., Marcovina, S.,Reynolds, K.,Yi-Frazier, J., & Mayer-Davis, E.J. 2014. Prevalence of and Disparities in Barriers to Care Experienced by Youth with Type 1 Diabetes. The Journal of Pediatrics Vol. 164, No.6, 1369-1374.

Vanelli,M., Munari,A., Fabbri,D., Iovane,B., Scarabello, C., Dodi, I., Mastrorilli, C.,Fainardi, V., Mauro, D.D. & Caffarelli, C. 2018. Could infantile interactive drawing technique be useful to promote the communication between children with Type-1 Diabetes and pediatric team? Acta Biomed. Vol.89, No.2. 1-8.

Viklund,G. & Örtqvist, E.2014. Factors predicting glycaemic control in young persons with type 1 Diabetes. John Wiley & Sons.Vol.11,No.3. 77.

Yafi,M. 2015. Lost in translation. JOHN WILEY & SONS Ltd.VOL. 32 NO. 3. 92. https://onlinelibrary.wiley.com/doi/abs/10.1002/pdi.1931

APPENDICES

Appendix 1:Questionnaire

Children Age:___

Questionnaire for type 1 Diabetes patients or their families:

Open Question:

Please write below what factors you think would be an influence on you to receive guidance from the nurse?

Closed Question:

In the following options which factor will be a reason to affect you to receive guidance from nurses?

1. Communication:
   - Nurse speaks a different language from the patient.
   - Nurses use complicated medical languages
   - Nurses use incongruent verbal and non verbal expressions
   - Nurses do not follow your family language
2. Guidance Method:
   - Video contents
   - Video games
   - Peer group interaction
   - Simulator
3. Family influence: Parents involvement in guidance
4. Age:
   - Children knowledge and abilities to take care of themselves
   - Puberty related issues
   - Age of the nurse
5. Gender: Gender of the nurse
6. Caring environment:
   - Hospital environment
   - Playing opportunity in hospital environment
   - Nurses are supportive and helpful
   - Allow peer group interaction
7. Nurse attitude:
   - Nurse's way of talking
   - Nurses are approachable
   - Nurses respect patients opinion
8. Patient nurse relationship:
   - Nurse has smile on face while talking

- Nurses communicate actively

9. Psychological:
   - Feel stressed and anxious when you got to know about your disease.
   - Stress or other feelings affect you when receiving guidance.
   - Nurses gives awareness to cognition and emotions.
   - Underlying mental health condition.
10. Race and culture:
   - Nurse and patient have religious difference
   - Nurse is from a different country
   - Nurse has different beliefs and culture from the patient.
11. Multiple knowing:
   - Time that nurse provides guidance
   - Patient’s reading skills
   - Patient’s calculation skills
   - Patient’s motivation to learn
   - Patient’s literacy level

Appendix 2:Information Paper

Study title: Guidance methods for patient younger than 18 years old

1. Invitation letter:

You are being invited to take part in a research study being conducted by students XING QIANNI and OLUWATOBI FAITH ADU from Lapin Ammattikorkeakoulu, Kemi. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like further information. Take time to decide whether or not you wish to take part. Thank you for reading this.

2. Purpose of research:

In Finland, Diabetes is seen as a major public health problem. It affects the quality of life of those who have the diseases and increases the mortality rate in the country. Presently in Finland, the number of children and young people developing Diabetes is growing higher. Type 1 Diabetes is more common in Finland than in any other country, apparently due to the Finnish gene family.

The purpose of this thesis is to explore the factors which could influence the quality of guidance. The aim of this thesis is to help health care-givers to improve guidance for Children with type 1 Diabetes. Different guiding factors will be studied,in the interview of the children, from these factors, we will find out the most effective factors of the guidance, to make the children receive fully the proper guidance for the management of their Diabetes.

3. Why have I been chosen?

You have been chosen because you are children with type 1 Diabetes and are visiting Mehiläinen Länsi-pohjan Keskussairaala Poliklinikka.

4. Do I have to take part in the research?

It is up to you to decide whether or not to take part in the research. If you decide to take part, you will be given this information sheet to keep and be asked to sign the consent form, even if you decide to take part, you are free to withdraw at any time without giving a reason. The decision to withdraw at any time, or the decision not to take part will not affect you in any way.

5. Will my taking part in this study be kept confidential?

All information received will be treated as confidential. Your name and age will not appear on the questionnaire, instead a code number will be used to identify you, questionnaire data will be input onto a datasheet, that can be accessed only by the research team.

6. What do I have to do?

You will be given two questionnaires with the same question. On the first paper you are going to get an open-ended question which you will be asked to give your own opinion. On the second questionnaire, there are going to tick boxes which you think is important for you. All the procedure will last less than 15 min, and after you finish your questionnaire, please return it back to diabetic nurses or researchers.

7. What will happen to the results of the research study?

The findings will be used in our thesis. As written earlier, the result will be reported in a way that preserves confidentiality. it will be the responsibility of the research team to collect and analyse all data.

For further information please ask diabetic nurses or researchers who give you this paper. After signing the consent paper, please return it back to the researchers or Diabetes nurses.

If you have any questions do not hesitate to contact us.

Thanks for your participation !

CONSENT PAPER:

☐ I have read the information sheet, and I had the opportunity to consider information, ask questions and have answered these satisfactorily.

☐ I agree to take part in the above study. I understand that my participation is voluntary and I am free to withdraw at any time without giving any reason, without my healthcare/education/work circumstances or legal rights being affected.

☐ I understand that direct quotes may be used when the project is written up, although they will be anonymized.

Appendix 3: Opinnäytetyön aihe: Hoito-ohjeistus alle 18-vuotiaille potilaille

1. Kutsu tutkimukseen

Sinut on kutsuttu osallistumaan Lapin Ammattikorkeakoulun Kemin opiskelijoiden XING QIANNI:n ja OLUWATOBI FAITH ADU:n laatimaan tutkimukseen.
Ennenkuin teet päätöksen osallistumisesta on tärkeää, että ymmärrät miksi tutkimus tehdään ja mitä siihen sisältyy. Lue alla oleva tiedote huolellisesti, ja keskustele siitä halutessasi muiden kanssa. Jos jotain jää epäselväksi tai haluat lisätietoa tutkimuksesta, ota meihin yhteyttä. Mieti rauhassa, haluatko osallistua tutkimukseen. Kiitos kun luet tämän!

2. Tutkimuksen tarkoitus:

Suomessa diabetesta pidetään yhtenä suurimmista kansanterveysongelmista. Se vaikuttaa diabetesta sairastavien elämänlaatuun, ja nostaa maan kuolleisuuslukuja. Tällä hetkellä diabetekseen sairastuvien lasten ja nuorten määrä kasvaa jatkuvasti Suomessa. Tyypin 1 diabetes on yleisempi Suomessa kuin missään toisessa maassa, ilmeisesti johtuen suomalaisesta geeniperimästä.

Tämän opinnäytetyön tarkoituksena on tutkia niitä tekijöitä, jotka voivat vaikuttaa diabetes-ohjauksen laatuun. Tämän tutkimuksen päämääränä on auttaa hoitajia parantamaan 1-tyypin diabetesta sairastavien lasten hoitoon liittyvää ohjeistusta. Lapsia haastatellessa tutkitaan erilaisia ohjausmenetelmiä. Näistä menetelmist? Sitten etsit tehokkaimmat tavat, jotta lapset saavat juuri oikealaisen ohjauksen diabeteksen hoitoon.

3. Miksi juuri minut on valittu?

Sinut on valittu, koska sinulla on 1-tyypin diabetes, olet alle 18-vuotias ja olet käymässä Mehiläinen Länsi-pohjan keskussairaalan poliklinikalla.

4. Täytyykö minun osallistua tutkimukseen?

On täysin sinun itsesi päätttävissä, osallistutko tutkimukseen vai et. Jos päätät osallistua, sinulle annetaan tämä tiedote mukaan, sekä pyydetään allekirjoittamaan suostumuskaavake. Jos päätät osallistua, voit lopettaa tutkimuksen koska tahansa, ilmoittamatta mitään syytä. Tutkimuksen lopettaminen kesken tai päätös olla siihen osallistumatta ei vaikuta sinuun millään tavalla.

5. Onko osallistumiseni tähän tutkimukseen täysin luottamuksellista?

Kaikki saatu tieto käsitellään luottamuksellisena. Nimesi ja ikäsi ei näy kyselykaavakkeessa, vaan tietosi tunnistetaan koodinumeron avulla. Kyselyn tiedot tallennetaan sähköisesti niin, että vain tutkimuksen tekijöillä on pääsy niihin.

6. Mitä minun täytyy tehdä?

Sinulle annetaan kaksi kyselykaavaketta (A ja B), joissa on sama kysymys. Ensimmäisessä kaavakkeessa saat vastata vapaasti, toisessa on monivalintakysymyksiä. Vastaaminen kestää noin 15 minuuttia, sitten voit palauttaa kaavakkeet diabetes-hoitajalle tai tutkijalle.

7. Mitä tutkimuksen tuloksille tapahtuu?

Tutkimustuloksia tullaan käyttämään opinnäytetöissämme. Kuten jo kerroimme, tulokset raportoidaan niin, että luottamuksellisuus säilyy joka vaiheessa. Kaikki tiedon kerääminen ja analysointi on tutkimusryhmän vastuulla. Lisätietoja saat diabetes-hoitajalta tai tutkijalta, joka antaa sinulle tämän tiedotteen. Kun olet allekirjoittanut suostumuskaavakkeen, palauta se diabetes-hoitajalle tai tutkijalle.

jos sinulla on kysyttävää, ota rohkeasti meihin yhteyttä!

Kiitos osallistumisestasi!

Suostumuskaavake alle 18-vuotiaiden 1-tyypin diabeteksen hoito-ohjeistuksen parantamisen tutkimukseen:

SUOSTUMUSKAAVAKE

☐ Olen lukenut tiedotteen, minulla oli mahdollisuus miettiä asiaa, esittää kysymyksiä ja saada niihin riittävät vastaukset.

☐ Suostun osallistumaan yllämainittuun tutkimukseen. Ymmärrän, attä osallistumiseni on täysin vapaaehtoista, ja voin lopettaa sen koska tahansa antamatta mitään syytä. Lopettaminen ei vaikuta mitenkään hoito- koulutus- tai työ-olosuhteisiini, eikä laillisiin oikeuksiini.

☐ Ymmärrän, että kun tutkimus kirjataan ylös, suoria lainauksia saatetaan käyttää, mutta niistäkään ei käy ilmi kenenkään henkilöllisyys.

Appendix 4: Kyselykaavake 1-tyypin diabetesta sairastavalle lapselle, hänen huoltajalleen tai perheelleen.

Lapsen ikä: _____

A: Kirjoita alapuolelle, millaisilla asioilla ja keinoilla olisi vaikutusta sinuun saadessasi diabetes-ohjausta hoitajalta?

B: Alla on 11 monivalintakysymystä. Valitse kustakin kohdasta ne vaihtoehdot, joilla on mielestäsi vaikutusta hoitajien antamaan diabetes-ohjaukseen.

1. Suullinen kanssakäyminen/ Kommunikaatio:

☐ Hoitaja puhuu eri kieltä kuin potilas

☐ Hoitaja käyttää vaikeaa lääketieteellistä kieltä

☐ Hoitaja käyttää yhteensopimattomia suullisia ja ei-suullisia ilmaisuja

☐ Hoitaja ei puhu perheenne "omaa" kielt?

2. Ohjauksen menetelmät:

☐ Videosisällöt

☐ Videopelit

☐ Vuorovaikutteinen eli interaktiivinen vertaisryhmä

☐ Simulaattori

3. Perheen/ huoltajan vaikutus:

☐ Vanhempien/ huoltajan osallistuminen ohjaukseen

4. Ikä:

☐ Lapsen tietämys ja taidot pitää huolta itsestään

☐ Murrosikään liittyvät aiheet

☐ Hoitajan ikä

5. Sukupuoli:

☐ Hoitajan sukupuoli

6. Hoitoympäristö:

☐ Sairaalaympäristö

☐ Mahdollisuus leikkimiseen sairaalaympäristössä

☐ Hoitajat ovat avuliaita ja tukevat sinua

☐ Vuorovaikutteinen vertaisryhmä voi kokoontua

7. Hoitajan asenne:

☐ Hoitajan puhetapa

☐ Hoitajia on helppo lähestyä

☐ Hoitaja kunnioittaa potilaan mielipidettä

8. Potilaan ja hoitajan välinen suhde:

☐ Hoitaja hymyilee puhuessaan

☐ Hoitaja keskustelee kanssasi aktiivisesti

9. Psykologia:

☐ Hermostuit ja stressaannuit, kun sait tietää sairaudestasi

☐ Stressi tai muut hankalat tunteet vaikuttavat sinuun, kun saat ohjausta

☐ Hoitajat huomioivat tunteesi

☐ Mielenterveyden tilaan kiinnitetään huomiota

10. Kansallisuus ja kulttuuri:

☐ Hoitajalla ja potilaalla on uskonnollisia eroja

☐ Hoitaja on eri maasta

☐ Hoitajalla on eri uskomukset ja kulttuuritausta kuin potilaalla

11. Yleistiedot:

☐ Ajankohta jolloin hoitaja tarjoaa ohjeistusta

☐ Potilaan lukutaito

☐ Potilaan laskentataidot

☐ Potilaan oppimishalut

☐ Potilaan luku- ja kirjoitustaidon taso