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Having a parent with Type 1 diabetes: Exploring young children's knowledge and thoughts about the disease

Master's thesis in Clinical Health Science - Obesity and Health

Supervisor: Ellen Margrete Iveland Ersfjord

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Kunnskap for en bedre verden

Sammendrag

Bakgrunn: Det mangler forskning på små barns opplevelser av å ha en forelder med type 1 diabetes (T1D). Barn har i henhold til barnekonvensjonen rett til å uttrykke seg om saker som angår dem. Likevel inkluderes ikke norske barn av foreldre med T1D i pårørendeundervisning, med mindre forelderens etterspør det. Det er viktig å erverve kunnskap om hvordan yngre barn opplever å ha en forelder med T1D.

Mål: Målet med denne studien var å undersøke unge norske barns (5-8 år) kunnskap og tanker om å ha en forelder med T1D, i forhold til om de bør inkluderes i pårørendeundervisning.

Metode: For å utforske barnas perspektiver ble det anvendt en kvalitativ tilnærming, inspirert av metoder ofte brukt innen barndomssosiologien. Metodene brukt var brainstorming, assosiasjonsoppgave, kroppskart- og diabetesutstyr og kostholdsoppgave. Semistrukturerte intervjuguiden ble også utviklet til de deltakerbaserte oppgavene. Barna inkludert i studien var mellom 5-8 år gamle, og hadde minst en forelder med T1D. Tolv barn deltok i studien, seks gutter og seks jenter. Tematisk analyse ble brukt for å analysere dataene.

Resultater: Alle barna hadde kunnskap om forskjellige aspekter ved T1D, med forskjellig bredde angående to hovedtemaer: (a) kunnskap om medisinsk utstyr og sykdomsmekanismer, (b) kunnskap om forholdet mellom T1D, kosthold (sukker) og potensielle komplikasjoner. Barnas kunnskap var ikke aldersrelatert, og noen av barna hadde dybdekunnskap om sykdommen. Deres kunnskap virket å være relatert til hvordan og hva forelderens lærte dem om T1D, barnets individuelle nysgjerrighet og interesse, og forelderens historie med fluktuerende blodsukker-verdier. Forelderens sykdom påvirket flere av barna og deres hverdag, noe som førte til bekymringer om forelderens sykdom hos to av de eldste barna.

Konklusjon: Funnene tyder på at små barn bør involveres i pårørendeundervisning. Informasjon om T1D kan trolig gi barn en større følelse av kontroll og delaktighet, i tillegg til mestringsstrategier for å håndtere forelderens diagnose. Det bør også utvikles et rammeverk for hvordan barn skal involveres i pårørendeundervisning angående T1D. Rammeverket bør baseres på kunnskap fra denne og fremtidige studier innen fagfeltet, i tillegg til innsikter fra barndomssosiologien og annen forskning på barns perspektiver om helse og sykdom.

Summary

Background: Research on young children's experiences of having a parent with Type 1 diabetes (T1D) is lacking. According to the UN Convention on the Rights of the Child,

children have the right to express their opinions about matters that affect them. Even so, children in Norway are only included in next of kin education if requested by the parent who suffers from T1D. It is important to gain knowledge about how younger children cope with having a parent with T1D.

Aim: The aim of this study was to explore young Norwegian children's (5-8 years old) knowledge and thoughts about having a parent with Type 1 diabetes (T1D), and whether they should be involved in next of kin education.

Methods: A qualitative approach, inspired by methods often used within the sociology of children and childhood, and participatory, child-friendly methods adjusted to the children's age group, were developed to explore the children's views. The methods used were brainstorming, association exercise, body map and diabetes supplies, and a diet exercise. Semi-structured interview guides to all participatory tasks were also developed. Children included in the study were between 5-8 years old, and had at least one parent with T1D. Twelve children participated, six boys and six girls. Thematic analysis was used to analyze the data set.

Results: All the children had knowledge about different aspects regarding T1D, with different breadth about two main topics: (a) knowledge about medical equipment and disease mechanisms, (b) knowledge about the relationship between T1D, diet (sugar), and potential complications. I found that children's knowledge was not age-related, and that some children had in-depth knowledge about the disease. Their knowledge seemed related to how and what the parents taught them about T1D, to the individual child's curiosity and interest, and the parent's histories with fluctuating blood sugar levels. Several children were affected by their parents' diabetes in their daily life, leading to worries about their parent's disease in two of the oldest children.

Conclusion: These findings suggest a need for involvement of young children in next of kin education. Information about T1D might give children a greater sense of control and agency as well as coping strategies to deal with their parent's diagnosis. Additionally, these findings suggest a need for the development of a framework on how to involve children in next of kin education about T1D. This framework should be built on knowledge from this study and future research within this topic, as well as establishing insights from social studies of children and childhood and other research on children's perspectives on health and illness.

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Having a parent with Type 1 diabetes: Exploring young children's knowledge and thoughts about the disease

Abstract

Research on young children's experiences of having a parent with Type 1 diabetes (T1D) is lacking. In this article, I explore young Norwegian children's knowledge and thoughts about the disease. I found that children's knowledge was not age-related, and that some children had in-depth knowledge about the disease. Their knowledge seemed related to how and what the parents taught them about T1D, the individual child's curiosity and interest, and the parent's history with fluctuating blood sugar levels. Several children were affected by their parents' diabetes in their daily life, leading to worries about their parent's disease in two of the oldest children. This suggests a need for involvement of young children in next of kin education.

Keywords

Type 1 diabetes (T1D), young children's experiences, social studies of children and childhood, next of kin education

Introduction

In this article, I explore young Norwegian children's (ages 5-8 years) experiences of having a parent with Type 1 diabetes (T1D), and whether young children should be involved in next of kin education. People with T1D can suffer from frequent and serious complications, and this can affect the whole family, including children (World Health Organization, 2016). One study examined children's (ages 10-17) roles in parent's diabetes self-management (Laroche et al., 2009), and another children's (ages 10-17) thoughts and feelings about dietary changes in the home during their parent's diabetes intervention (Laroche et al., 2008). However, there seems to be a lack of research on young children's (below 10 years of age) experiences of having a parent with diabetes. According to the UN Convention on the Rights of the Child from 1989,

children have the right to express their opinions about matters that affect them (UN, 1989). Even so, children in Norway are only included in next of kin education if requested by the parent who suffers from T1D. It is important to gain knowledge about how younger children cope with having a parent with T1D. The social studies of children and childhood, which uses methods for exploring children's worlds and point of views (James and Prout, 1997) is an appropriate approach for this.

Research by Sanders et al. (2018) shows that young adults with T1D often feel misunderstood by those around them. They may also experience feelings of guilt and irritation related to their diagnosis, and a desire to keep the disease a secret. Another study (Fisher et al., 2015) shows that adults with T1D can struggle with feelings of powerlessness, worries about how others perceive them, distress and disappointment related to their practitioner, and worries regarding how their family gets involved in their disease. Additionally, they may experience worries related to blood glucose management, food, and general handling of the disease. Jönsson et al. (2015) found that children with T1D, aged 5-7 years old, had more concerns related to their diagnosis than children in older age groups. This suggests that a lack of information and knowledge about T1D can raise feelings like anxiety and fears for children. It is therefore important to examine whether and how children, aged 5-8 years, who have a parent with T1D, might have concerns. In this article, I explore the question: How do children in the age of 5-8 years old experience having a parent with T1D, and what understanding and knowledge do they have about the disease?

My work is situated in the social studies of children and childhood, where childhood is understood as socially constructed and in which children are understood as social agents who can affect their own lives (James and Prout, 1997). Inspired by methods often used within this framework, I developed child-friendly methods to explore the children's views.

My study shows that all children knew of some or all medical equipment used by parents in their diabetes treatment. Some children knew of disease mechanisms related to T1D, but at varying degrees. The majority had some knowledge about relationships between T1D, diet (sugar) and potential short-term complications. In general, the children's breadth of knowledge was not age-related, but rather connected to how and what the parents taught the child about T1D, to the individual child's curiosity and interest, and experiences of their parent's histories with fluctuating blood sugar levels. Two of the oldest children expressed severe worries related to their parent's T1D. My findings suggest a need for involvement of young children in next of kin education. This might give them a greater sense of control and agency as well as coping strategies.

Children and health within the social studies of children and childhood

Within social sciences, research regarding children's health has traditionally focused on parents' and health-care workers' perspectives of a child's disease management (James and Prout, 1997; Brady et al., 2015). Knowledge regarding children's perspectives about chronic illness was scarce (Herrman, 2006). Over the last decades however, researchers have increasingly focused on inclusion and involvement of children (Trondsen, 2012). The social studies of children and childhood has been at the forefront by exploring children's perspectives on health and illness (Brady et al., 2015). Brady et al. (2015) emphasize that we cannot fully understand the meaning and impact of health and illness without considering children's perspectives.

Research shows that children with T1D want to learn about their disease, and that they alternate between being a "passive bystander" and an "active participant" in their diabetes treatment (Ekra et al., 2015). Other studies show similar findings (e.g., Curtis-Tyler, 2012; Koller et al., 2015; Tyler, 2009). One study (Alderson et al., 2006) found that children as young as four years old with T1D were competent at making decisions in their best interest, due to their experiences with the disease. Similar findings were observed in Brady's (2014) study regarding children's management of ADHD, where decision-making was linked to competence and knowledge.

To my knowledge, no research has explored young children's experiences of having a parent with T1D. There is, however, research on children with a parent who suffers from other chronic medical conditions (CMC) that might be transferable. In 2010, Sieh et al. found that children with a parent with a CMC are more likely to struggle with both internalizing and externalizing problem behaviour compared to children with a healthy parent. Younger age in children and parents, low socioeconomic status and long illness duration are also linked to increased risk of behavioural problems for children. Another study (Trondsen, 2012) shows that children, aged 15-18, with a mentally ill parent have questions about their parent's illness, leading to fear, loneliness, instability and sorrow in their daily lives. Research also shows that children of a parent with a CMC might take on caring responsibilities for their parent. Some studies have found the level of caring responsibilities to be linked to the children's age (Webster, 2018; Dearden and Becker, 2004), while others have found age to be less important (Aldridge and Becker, 1993). Webster (2018) argues that the level of responsibility seemed to be linked to parents' perceptions of the children's ability to take on responsibility. Studies show that caring responsibilities can negatively impact children's

social networks, education, employment opportunities and mental health (Aldridge, 2008), as well as positively affect coping skills, family relationships and maturity (Aldridge and Becker, 2003). Thus, there is consensus that children are affected by having a parent with a chronic illness, which underlies the importance of exploring children's experiences, needs, thoughts, understanding and knowledge of having a parent with T1D.

The social studies of children and childhood emphasizes the importance of conducting research with children, focusing on the children's voices and perspectives (Brady et al., 2015). Research on children's perspectives of health and illness shows that children's perspectives often differ from those of adults, and that children's competencies around a diagnosis often is underestimated (Brady, 2014; Alderson et al., 2006; Jönsson et al., 2015; Sieh et al., 2010). With this in mind, I explored what knowledge the children have about T1D and disease mechanisms, medical equipment, and the relationship between T1D, diet (sugar), and potential complications. Additionally, I have explored the children's feelings, thoughts and worries regarding their parents' T1D.

The objective was so to shed light on children of a parent with T1D and explore whether young children should be involved in next of kin education. My findings suggest that even young children might have in-depth knowledge regarding their parents' disease and that children are affected by their parents' T1D in their daily life. This suggests a need for involvement of young children in next of kin education to teach them coping mechanisms and limit stress.

Materials and methods

This study was initiated by a nurse at a Department of Endocrinology in collaboration with a researcher working at the same hospital. They both contributed to the recruitment of children, using purposive sampling. Some parents were contacted directly by the Department of Endocrinology. Others were contacted by The Norwegian Diabetes Association, and through social media; the Hospital's Facebook page (FB), The Norwegian Diabetes Association's national and local FB, and a Healthy Life Centre's local FB.

A qualitative approach, inspired by methods used within the sociology of children and childhood, was used to explore the children's experiences. Participatory, child-friendly methods, adjusted to the children's age group, were developed to explore children's views. Semi-structured interview guides to all participatory tasks were also developed.

The data was collected over a period of two months. Data collection was conducted in- and around a Norwegian city. Children included in the study were between 5-8 years old, and

had at least one parent with T1D. Twelve children participated, six boys and six girls. Four children had a sibling who met the inclusion criteria, and these were also included. In total, I visited eight households. All the interviews were performed in their home, preferably in the child's room. This was done to ensure an environment where the child would feel safe and confident, and to even out the power imbalance between the child and me. No parent(s) were present during the interviews in order to ensure that I collected the children's views and perspectives, not the parents'.

On arrival, I always had a conversation with the parent(s) and the child(ren) participating in the study, telling them about the rationale behind the interview and the tasks at hand. I also informed both parents and the child(ren) that they could withdraw at any time or not answer my questions. I reassured the child(ren) that there were no right or wrong answers, and that they could answer in detail or not.

All participatory methods used built on- and complemented each other in order to explore the research question from different angles. The methods were flexible in relation to time and implementation, depending on the individual child's reactions and needs during the session, and whether or not he/she revealed interesting findings that needed further investigation. The methods used were brainstorming, association exercise, body map and diabetes supplies, and a diet exercise.

During **Brainstorming**, I asked the child: *What are your thoughts about the word diabetes?* This exercise gave insight into the child's knowledge related to diabetes, and set the stage for further exercises.

In the **Association exercise**, I showed the child pictures of different diabetes supplies, like a blood glucose meter, an insulin pen- and an insulin syringe, and asked if he or she recognized any of the supplies.

In the task called **Body map and diabetes supplies**, the child got handed a piece of paper containing the same pictures as in the association exercise, plus a body map. The child was then asked to place lines between the body map and the pictures, to illustrate how/where the equipment is used on the body.

In the **Diet exercise**, I handed the child two pictures: One of a smiley face, the other of a thinking face. I then gave the child a stack of smaller food pictures and told the child to place them on the two different faces in accordance to what food he/she thought his/her parent should eat a lot of (smiley face), and less of (the thinking face). I specified to the child that he/she should place the food pictures based on how he/she thought the parent should eat considering his/her T1D; not based on what the parent prefers.

After or during the activity-based methods, I asked the child questions from my semi-structured interview guide or other relevant follow-up questions based on the children's answers. I further asked the child how he/she felt about having a parent with T1D. The main questions were: Do you think about that mommy/daddy has diabetes often? Does mommy/daddy talk about diabetes to you? If so, what do they say? Have you ever experienced mommy/daddy getting ill because of diabetes? What happened? Did you then know that it was because of diabetes? What were your thoughts/feelings when it happened? Has it happened several times?

Each interview lasted 14-40 minutes, depending on the child's knowledge about the theme, ability to concentrate, and on whether he/she seemed to enjoy the interview. All interviews were recorded and transcribed. Pictures of all the activity-based tasks were taken and collected for further analysis.

To develop the participatory methods and semi-structured interview guide, and to ensure a comprehensive yet open-minded approach, I regularly met with my supervisor. We also met during the period of the data collection, coding of data and discussed relevant findings. Thematic analysis was used to analyze the data set.

Following the steps in thematic analysis, I started by transcribing the interviews, and taking notes about themes and comments that seemed relevant for later analysis. I then searched for repetitions, patterns, and other clues that guided me towards incidents of meaning within the different parts of each transcription, leading to text segmentation and coding of these segments. After that, I grouped text segments with similar codes, comparing them to identify fitting overarching themes and sub-themes. These themes were discussed and critically re-evaluated by me and my supervisor several times until the final themes were identified and redefined into precise themes with punchy titles (Guest et al., 2012).

I started analysing the data after having finished the five first interviews. I did this to ensure high-quality data, and to facilitate potential adjustments in later interviews. I realized that some children had been confused in the association exercise, and made adjustments to the pictures presented in the exercise. I also became aware of situations where the exercises should have been explained in a more child-friendly manner, and adjustments were made. After eight interviews, little new information appeared. By the twelfth interview, I experienced data saturation, and stopped data-collection.

This study was evaluated by the Regional Committees for Medical and Health Research Ethics in Norway and was approved by the Norwegian Social Science Data Services. I obtained informed consent from parents. Children and parents received written and

verbal information about the study and were informed that they could withdraw at any time without any consequences for treatment. The informed consent form was developed according to the Declaration of Helsinki (WMA General Assembly, 1964). All parents were able to read the interview guide during the recruitment process.

The children's knowledge about the disease

By using child-friendly participatory methods, I gained insight into the children's knowledge about T1D. All the children had knowledge about different aspects regarding T1D, with different breadth about two main topics: (a) knowledge about medical equipment and disease mechanisms, (b) knowledge about the relationship between T1D, diet (sugar), and potential complications.

Knowledge about medical equipment and disease mechanisms

Almost all the children had some knowledge related to their parent's medical equipment. Depending on which medical equipment their parent used, some children talked about "a pen" (insulin syringe), others talked about "a receiver" (connected to a sensor) that shows blood glucose levels, some talked about "a pump", some talked about "a manual blood glucose measurer", and some used a combination of these terminologies.

Regarding mechanisms involved in T1D, the majority had little advanced knowledge, meaning that no one explained diabetes in lines of typical medical terms, like how T1D is a condition in which the immune system destroys insulin-making cells in the pancreas (International Diabetes Federation, 2020). Still, a few children had some knowledge about the mechanisms. For example, out of the five children who had seen their parent use a pen, Noah, six years old, knew that the pen (Insulin syringe) I showed him a picture of was "a syringe for Insulin, because that thing in the body (i.e. the pancreas) does not work". Noah also told me that his father had "told him what happened when he got diabetes", and that he sometimes assisted his father during injections.

The children of parents who used sensors, all knew that "that thing" was involved in checking blood sugar levels, and a majority knew that low or high blood sugar was bad for the parent. Olivia, aged five years old, also had knowledge about the disease, as she stated during the association exercise:

Olivia: He has one of those (pointing to her arm), which makes him... It is a substance that he does not make himself.

Me: “Yes...?”

Olivia: So he needs help for making it. It is inside the syringe, and it does not hurt”.

In this quote, we see that Olivia knows that her father has a sensor connected to his arm for measuring blood sugar, and she knows that there is something wrong with her father’s body, not making a substance he needs, i.e. Insulin. She also knows that this “substance” is inside the syringe.

All children of parents who used insulin pumps (nine children in total) had seen their parent’s pump, however their knowledge regarding why the parent needed the pump and how it functioned varied. William, seven years old, knew that his mom needed Insulin, and that she got it from the pump. However, he did not seem to understand what Insulin was or why she needs it. Another boy named Oliver, eight years, thought his mom needed the pump to know when she should be eating sugar or other stuff. When Ava, seven years old tried to draw lines between the body map and the illustration of a pump in the body map and diabetes supplies task, she said “I have no idea where it goes really”, and she had little knowledge about its functions. Ava however, seemed to have some deeper understanding of the disease mechanisms, stating there was: “a thing inside the body that does not work”, meaning the pancreas, but she could not remember the medical term for it. Other children had vague answers when I asked them what their thoughts were about the word diabetes during the first exercise. For example, Caroline, aged five, answered “but I do not know what it means”, when I asked for her thoughts about the word diabetes during the brainstorming exercise, expressing that she did not understand what diabetes was. She did not seem to know that her mom had diabetes either, only that her mom had a pump on her hip, without knowing its functions. Another five-year-old, Mia, answered “I don’t know”, during the same exercise, not having any initial thoughts on the subject. However, it became evident later in the interview that she had some knowledge about the functions of the pump and sensor that her mother used.

During the association exercise, some children who were given the picture of the manual blood glucose measurer said that their parent used it. It became clear from this exercise that some parents used a manual blood glucose measurer in combination with their sensor or pump. Once more, most children of these parents had seen the measurer, but did not know its functions or why the parent used it. Two children (Mia and Noah) had seen their parent prick their fingers and bleed, without knowing why the parent did that. When I asked Noah during the association exercise if he knew why his father had to have a dot of blood, he

answered “no” followed by “he wipes it away again”. Only Ava seemed to have some deeper knowledge about the functions of the blood glucose measurer, saying that her mother would use it to prick her finger to measure the blood glucose level, and that the measurer had a “white thing” that she would put the blood drop on, and that this thing would measure her blood sugar level.

To sum up, all children had seen their parent use medical equipment in their diabetes treatment. Almost all children had some knowledge about the medical equipment that their parent used. Some children had little knowledge about the functions and the use of the equipment, and some had deeper knowledge. This was also the case for those who had knowledge about disease mechanisms. Knowledge about disease mechanisms and medical equipment did not seem related to the children’s age, but may have been related to how the parent taught the child about T1D and involved the child in his/her treatment.

Knowledge about the relationship between T1D, diet (sugar) and potential complications

By using participatory methods, I learned about the children’s knowledge regarding the relationship between T1D, diet and potential complications. Most children said they ate much of the same food items as their parents, but that there was a difference between how much sugar they and their parent with diabetes could eat; sugar was a recurring theme.

The children had different thoughts about how sugar intake varied between themselves and their parent, with several children saying that they thought they could eat more sugar than their parent. For example, when I asked Oliver whether there was a difference between what he and what his mother could eat, he said:

Oliver: Big difference.

Me: Yes... in which way?

Oliver: For example, that, when we eat ehm dessert, then my mom does not take so much, she only takes like two, tree spoons.

Me: Ok, yes... Mmm. While you eat as much as you’d like?

Oliver: (Smiling)

Oliver continued saying that he thought his mother would faint if her blood sugar became too high. He also told me that his parents would argue sometimes, and that he thought it was related to his mother’s blood sugar levels. This indicates that he has some understanding of

consequences related to high blood sugar, and of how fluctuations in blood sugar levels might affect mood swings.

Other children knew that their parent with diabetes could eat less sugar than themselves, but not why. For example, when I asked Lucas, eight years old, during the diet task if there were any differences between what he and his mom could eat, he said “Hm...ta-da!” (pointing at candy), but he could not explain why. When I later asked him if he thought he had seen his mom become ill due to her diabetes he said “she sometimes becomes dizzy and has headaches”, followed by “but I don’t know if that is related to her diabetes”. Caroline and Mia also said that their parent with diabetes would have “headaches”, but without stating that this was due to high blood sugar levels.

Overall, the majority had more understanding and knowledge about how low blood sugar affected their parent compared to how high blood sugar did, with nine children having knowledge about the effect of low blood sugar. For example, during the brainstorming exercise, Noah said “Sometimes he has to get more sugar (talking about his dad), and sometimes there is too much sugar in the body” followed by stating that his father had to “lay down on the couch and relax if he had low blood sugar”, and that he should “eat something to get better”, preferably something containing sugar. Later in the interview, during the body map and diabetes supplies task, he also told me that some food “gets into the blood”, without explaining this in more detail. During the association exercise, when I asked Ava if blood sugar levels could affect her mom in any way, she answered: “She can become fatigued. If she does not manage to help herself, then I must go and get sugar and if this does not work then I must call 113 (911)”. When I asked whether there was any difference between how much sugar she and her mother could eat, she answered: “Yes. For example, I can only eat sugar on Saturdays, while she can do it whenever”. Another seven-year-old girl named Nora, knew that her mom could experience fatigue and become cranky if she had low blood sugar and did not eat anything. She thought it was unfair that her mom could eat candy whenever she needed to:

Nora: Ehhm, I sometimes ask mom if I can get candy.

Me: Ok, haha.

Nora: Because sometimes I get a little annoyed if I don’t get candy.

Me: Ok, haha, yes

Nora: Because it has been such a long time ago since I have had it.

This suggests that Nora understands that her mom needs sugar due to her diabetes, but she still finds it unfair that her mom can eat sugar whenever she needs to.

Even though the majority knew that diabetes and sugar were related, most of the children had more knowledge about either high blood sugar alone, or low blood sugar alone. A few children had nuanced knowledge about both. Noah, Ava and Nora for example, all had knowledge about consequences of low blood sugar, but less understanding about how high blood sugar affected their parent's body. With Noah, this became evident during the brainstorming exercise:

Me: Does anything happen if your dad gets too much sugar in the body?

Noah: That, then he gets diabetic seizure, but then he has to eat, and if he has too much... like fructose or something then maybe he has to drink some Cola or something.

Me: Yes, ok.

Noah: With lots of sugar in it.

Me: Ok, yes, and this is both if he has too little or too much sugar in the body, or?

Noah: Mhm.

Here we see that Noah thinks low and high blood sugar levels affects his father the same way, and that equal measures are required to treat both types of fluctuations in blood sugar levels. This indicates that he has little understanding of high blood sugar and its impact on his father. Ava and Nora did not know how high blood sugar would affect their parent, but Nora knew that it could make her mom become ill, telling me that she might get "nauseous". Regarding the other children who had knowledge about complications of low blood sugar, some pointed out that sugar was bad for the body, but that it still could be beneficial for their parent with diabetes to eat sugar, indicating an understanding of the link between diet and diabetes. These children also claimed that they had not seen their parent become ill due to diabetes, and if they had, then it was due to low blood sugar. Considering this information, one could ask if most parents were more concerned with having low blood sugar compared to high blood sugar, or that the children did not notice when their parent had high blood sugar, due to its more diffuse symptoms.

There was however one girl who had more nuanced knowledge regarding the consequences of both high and low blood sugar. Olivia, aged five years old, knew this and explained it to me during the association exercise when she talked about the sensor on her

father's arm, saying that: "This one beeps if he has low blood sugar" followed by "and then he needs to get chocolate milk". She also said that:

Olivia: It alerts him if he gets too much sugar.

Me: Yes...

Olivia: Then the blood sugar gets THIS HIGH!!

Me: Ok!

Olivia: And then it is a little dangerous.

It became clear during the rest of the interview with Olivia that her father had struggled to maintain stable blood sugar levels. This might indicate that children who have nuanced knowledge about both high and low blood sugar are the ones with a parent who struggles with both types.

As we see, knowledge regarding consequences of too high or too low sugar intake varied among children, with most children having more knowledge about consequences related to low blood sugar compared to high blood sugar levels. Knowledge was not related to age but seemed to be connected to how and what the parent taught the child about T1D, the child's curiosity and interest, and the parent's history with fluctuating blood sugar levels. One interesting finding is that several children answered "no" when asked whether or not their parent ever had been ill due to his or her diabetes, contradicting their previous statements about their parent's issues regarding blood glucose management. No children talked about the importance of their parent maintaining stable blood sugar levels over time either. This indicates that their parent's unstable blood sugar is a constant and common part of their everyday life, making them not think of their parent as "ill" or "limited" when the parent has high or low blood sugar.

The children's feelings, thoughts and worries about T1D

No children mentioned thoughts about potential and serious long-term complications arising from their parent's diabetes, such as reduced sight or impaired blood circulation (WHO, 2016). Two boys, however, were worried that their parent could experience serious short-term complications. For example, when I asked Jacob, an eight-year-old boy, during the brainstorming exercise what his thoughts were about diabetes, he said: "I get a little bit sad because he can die", continued by saying that his father needed sugar "to get better again", and again he underlined that he was "worried that his father was going to die". He also expressed a fear of not having other adults around if his father got ill, saying: "Because, what

if mom does not know about it?. (I am) not able to lift daddy up...”, followed by telling me about different situations where his father had become ill due to low blood sugar levels.

The other boy, Oliver, told me that he was worried that his mom “was going to faint” if she did not pay attention to her blood sugar levels. However, he said that he had not seen his mother become ill as a consequence of her diabetes. Still, he had a lot of thoughts about it, which became evident when I asked him if he wanted to know more about diabetes, or if he felt that he knew enough:

Oliver: I know enough because I do not want to get scared.

Me: Ok, yes, do you think that you can become more afraid if you know more?

Oliver: (Nodding)

Me: Yes, do you think it is, is it ok for you to talk about it with me now or do you get a little bit scared when you talk about it with me?

Oliver: Not so scared, but in a way that I get so many thoughts in my head.

These two boys were two of the oldest children in the study. They were the only children who expressed worries about potential complications and situations that could occur as a consequence of their parent’s T1D. Neither had deep knowledge about T1D, or experienced situations with having to help their parent in any way. Some of the other younger children talked about just as many (or more) experiences of their parent being ill, and some also had in-depth knowledge about the disease, Ava for example. She knew that she needs to call 113 (911) if her mother becomes severely ill. However, none of the younger children had many worries related to their parent’s disease. Even though this study includes few children, one could ask if the worries experienced by two of the oldest children, Jacob and Oliver, is related to their age and cognitive development, rather than to knowledge about potential complications or experiences of illness episodes. This is also in accordance with other research on children’s worries in this age group; Wichstrøm et al.’s (2017) study found an increasing number of symptoms of anxiety disorders in children, aged 8-10 years, compared to the younger children in their study. Grist and Field’s study (2012) on children’s (ages 3-7 years) ability to worry, also found the seven year-old children more competent at worrying due to cognitive development.

Discussion

In this study, I have explored young children’s (ages 5-8 years) experiences of having a parent with Type 1 diabetes (T1D), and their understanding and knowledge about the disease. The

aim of the study was to explore whether young children should be involved in next of kin education in Norway. The social studies of children and childhood emphasizes the importance of conducting research with children, focusing on the children's own voices and perspectives (Brady et al., 2015). Child-friendly methods were used for exploring the children's views.

My findings show that children's knowledge is not age related; even young children might have in-depth knowledge regarding their parent's disease. I interpret the children's knowledge to be a result of several factors interacting and affecting each other. The most important mediating factors seem to be how and what the parents teach them about T1D, the individual child's curiosity and interest, and experiences of their parent's histories with fluctuating blood sugar levels. This is also in accordance with other research on children with T1D, showing that children often learn about diabetes-related procedures from their parents (Rankin et al., 2017; Curtis-Tyler, 2012), that the children's ability to perform some of the self-management tasks in their diabetes treatment are not age-related (Rankin et al., 2017; Koller et al., 2015; Alderson et al., 2006), and that experience is more important than age (Alderson et al., 2006; Brady, 2014). However, there are also studies that have found age to be a mediating factor on knowledge about diabetes (Rankin et al., 2017; Koller et al., 2015). This indicates that age should not be ignored in future research on this topic. Most importantly, these findings underlay that no universal childhood exists (Brady et al., 2015) and that researchers need to keep an open mind when they conduct research with children (Ekra et al., 2015). Also, children use different vocabulary than adults (Punch, 2002), and researchers need to keep this in mind when they choose research methods for exploring children's knowledge, as well as when analysing data.

My findings show that several children are affected by their parent's T1D in their daily life, with the youngest children being aware when their parent had symptoms of fluctuating blood sugar, and two of the oldest children worrying about their parent's disease. I argue that this illuminates a need to teach children about T1D (Jönsson et al., 2015), to prevent them from developing severe worries, and to limit stress in their daily lives (Wichstrøm et al., 2017; Grist and Field, 2012).

My research provides new insights and has several implications. First, my research can contribute to insights into younger children's experiences of having a parent with T1D and into the importance of teaching them about T1D to limit stress in their daily lives. Secondly, the incidence of Type 2 diabetes (T2D) and also gestational diabetes is increasing, and many people with T2D also use Insulin in their diabetes treatment (WHO, 2016). There will be an increasing number of children growing up with a parent who has Insulin-dependent diabetes

in the future. Considering that children are affected in different ways by their parent's chronic medical condition (CMC) (Trondsen, 2012; Sieh et al., 2010; Webster, 2018; Dearden and Becker, 2004; Aldridge and Becker, 1993; Aldridge and Becker, 2003; Aldridge, 2008), it would be relevant for future research to explore both how Insulin-dependent and non-Insulin dependent T2D affect children. Third, my findings suggest that the connection between age and worrying in children of a parent with diabetes needs to be better examined. Fourth, the inconclusive findings seen in research regarding age and knowledge in children suggest a need to explore this theme further. Finally, there has been an increasing focus within research on children's experiences of having a sibling with T1D (Jackson et al., 2008; Wennick and Huus, 2012), and my findings can provide insights for future research exploring if there are differences in experiences and needs for children who have a sibling compared to a parent with diabetes.

To conclude, future studies should explore younger children's needs for information about diabetes, both at home and by health professionals in the hospitals (Jönsson et al., 2015). Since children's worries about T1D seem linked to a lack of information about the disease (Jönsson et al., 2015), I argue for future involvement of young children in next of kin education about T1D, and a need for the development of a framework on how to do so. I propose a framework that is built on knowledge from this study and future research within this topic, as well as establishing insights from social studies of children and childhood and other research on children's perspectives on health and illness (see for example Ekra et al., 2015; Jönsson et al., 2015; Wennick and Huus, 2012).

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