

The pen, the receiver and the pump: Exploring young children's experiences of having a parent with type 1 diabetes

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Abstract

In this article, we explore young children's experiences of having a parent with type 1 diabetes (T1D). In our research we found that the children's knowledge about T1D was not age related, and that some had more in-depth knowledge than others. This seemed related to how and what the parents taught them about diabetes, 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. Our research contributes to knowledge about how children's lives can be affected by having a parent with chronic illness.

KEYWORDS

children, health & well-being, young carers

INTRODUCTION

In this article, we explore young Norwegian children's (ages 5–8 years) management, understanding and experience of having a parent with type 1 diabetes (T1D). T1D is an autoimmune disease where the immune system attacks and destroys cells in the pancreas where insulin is made (Katsarou et al., 2017). There is no cure for the disease (Pettus & Von Herrath, 2018). T1D frequently leads to serious complications like kidney- and heart diseases, blindness, stroke and lower limb amputation (WHO, 2016). Self-care and management of the disease is challenging; it requires knowledge about

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the disease and one has to master injecting insulin and navigating digitalised devices like insulin pumps and glucose monitors (Kingod & Grabowski, 2020).

Having T1D can affect the whole family, including children (WHO, 2016). Children's perspectives of having a parent with T1D is an under-researched topic, but a study of children's (ages 10–17) roles in parent's diabetes self-management performed by Laroche et al. (2009) showed that children can have many roles in supporting adult's diabetes self-management. They found that children often monitored parent's food intake and physical activity, and many helped their parent with shopping and meal preparation. This research suggests that children in this age group worry for their parent with T1D. Research also shows that parents can suffer from a constant state of worry for their children with T1D (Kingod & Grabowski, 2020) and may develop anxiety and depression (Grey, 2009). Many worry about the management of their child's blood glucose, food intake and general handling of the disease (Kingod & Grabowski, 2020). Since research suggests that older children as well as adults struggle with having a family member with T1D, how do young children cope with having a parent with T1D? In our study, the overall goal was to gain insight into how the children's lives were affected by having a parent with D1T. We sought to answer this by exploring the two following research questions: (a) What do younger children with a parent who has T1D know about T1D, and (b) how do they cope? Regarding children's knowledge about the T1D, we wanted to gain insight into their knowledge about medical equipment and disease mechanisms involved and their knowledge about the relationship between T1D, diet and potential complications. Regarding children's coping, we aimed at exploring their feelings, thoughts and worries about having a parent with T1D.

Our 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 & Prout, 1997). Inspired by methods often used within this framework, we developed child-friendly methods to explore the children's views.

THE SOCIAL STUDIES OF CHILDREN AND CHILDHOOD AND CHILDREN'S PERSPECTIVES OF HEALTH AND ILLNESS

Within social sciences, research regarding children's health has traditionally focused on parents' and health care workers' perspectives of a child's disease management (Brady et al., 2015; James & Prout, 1997). Knowledge regarding children's perspectives about chronic illness used to be scarce (Herrman, 2006). Over the last decades, however, researchers have increasingly focused on inclusion and involvement of children (Trondsen, 2012), and the social studies of children and childhood have been at the forefront by exploring children's perspectives on health and illness (Brady et al., 2015). This framework, which gained foothold in the 1980s and 1990s, stimulated this interest by criticising social science approaches that understood children in light of a 'universal' development (James & Prout, 1997; Nilsen, 2003). Instead of understanding children as 'unfinished' and 'incomplete' (Mayall, 1998, Tisdall and Punch, 2012) and as requiring social and cognitive skills to develop towards 'rational' adulthood (James & Prout, 1997), researchers introduced a social constructivist framework in which notions of children and childhood are understood as products of different worldviews (Jenks, 1992). Within this framework, it is now agreed that children are embodied health care actors (Mayall, 1998). The importance of listening to children's voices in order to understand the meaning and impact of health and illness on their lives is now recognised (Brady et al., 2015).

Regarding children's perspectives of having T1D themselves, research shows that children 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 4 years old with T1D were capable of making decisions in their best interest due to their experiences with the disease. Similar findings were observed in a study of children's management of ADHD, where decision-making was based on competence and knowledge (Brady, 2014). Considering that even young children show competence in their own disease or illness management, it might be reasonable to assume that young children also play a role in supporting adult's (parents) diabetes self-management.

Even though there has been no research, to our knowledge, on 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 (CMCs). In 2010, Sieh et al. (2010) found that children with a parent with a CMC are more likely to struggle with both internalising and externalising problem behaviour compared to children with a healthy parent. Another study performed by Trondsen (2012) shows that children, aged 15–18, with a mentally ill parent had many challenges relating to their parent's mental illness. They struggled with feelings of unpredictability and instability, as well as fear, loneliness, loss and sorrow. They also lacked information and openness about their parent's illness. Research also shows that children of a parent with a CMC might take on caring responsibilities for their parent. For example, a study of children 12–20 years old exploring the needs of young carers perspectives of living with a parent with Huntington's disease (HD), which is a progressive, genetic disorder with no cure, has shown that many assume caregiving tasks, affecting their health and well-being regardless of their age (Kavanaugh et al., 2015). Despite this, children do not necessarily want to stop doing caregiving tasks, but are rather concerned with seeking information and advice on caregiving (Ibid.). Regarding children's age and level of caring responsibilities, some studies have found this to be linked to the children's age (e.g. Dearden & Becker, 2004; Webster, 2018), while others have found age to be less important (Aldridge & Becker, 1993). Webster (2018) argued that the level of responsibility is rather linked to parents' perceptions of the children's ability to take on responsibility. Even so, 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 & 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 perspectives and experiences of having a parent with T1D.

The social studies of children and childhood emphasises 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 (Alderson et al., 2006; Brady, 2014; Jönsson et al., 2015; Sieh et al., 2010). With this in mind, we wanted to explore what children who have a parent with T1D know about T1D and disease mechanisms, medical equipment, and the relationship between T1D, diet (sugar) and potential complications. Additionally, we wanted to gain insight into how children cope with having a parent with T1D in their daily lives by exploring their feelings, thoughts and worries regarding their parents' condition. Our findings suggest that even young children can have in-depth knowledge regarding their parents' disease and that they all were affected by their parents' T1D, but to varying degrees. We also found that the oldest children expressed worries about complications and situations that could occur in relation to their parent's T1D. This suggests that even young children are affected by their parent's T1D in their daily lives, and that they need to learn and know about the condition to cope and avoid or limit (future) stress.

MATERIALS AND METHODS

This study was initiated by a nurse at a Department of Endocrinology at a university hospital in the mid-region of Norway in collaboration with second author, 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 local Healthy Life Centre's FB.

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

The data were collected by first author over a period of 2 months. Data collection was conducted in and around a Norwegian city. Children included in the study were between 5 and 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. The first author visited eight households. All the interviews were performed in participants' 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 the researcher. No parents were present during the interviews in order to ensure that the children's views and perspectives were collected, not the parents'.

On arrival, the first author 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. She also informed both parents and the child(ren) that they could withdraw at any time or not answer the interview questions. She reassured the child(ren) that there were no right or wrong answers, and that they could answer in detail or not.

As mentioned, methods used for data collection were inspired by methods often used within the framework of social studies of children and childhood, which tend to involve children themselves (Moss et al., 2005). Within this framework, children often do different activities and participatory tasks, and the researcher and the child have a subsequent discussion about the subject being explored (Clark, 2005). The use of participatory methods is linked to children's rights and the idea that researchers have a responsibility for making children's voices accessible to others, that is, that children's voices should be 'heard' (James, 2001). Also, it is considered important not to view children as research objects; researchers within this framework do research *with* rather than *on* children (James, 2001). The idea is that children should be studied 'in their own right', and they should be recognised as competent interpreters of their social world(s) (James, 2001).

The tradition of separating children from adults and focusing on children's perspectives only within the social studies of children and childhood has been criticised in recent years. It is, for example, said that it overlooks the reciprocal relationship between children and adults (Wyness, 2012), and especially in regard to children's needs for emotional support and caring relations from adults (Kjørholt et al., 2005). Gallacher and Gallacher (2008) point to how an understanding of children's participation as 'liberating' and 'democratic' for children can create methodological problems. They argue that it is in fact adults that empower children by using adult-designed methods for children's participation in the research. Encouraging children to participate in research to create knowledge about themselves is thus also to encourage them to take part in the process used to regulate them, and we can risk understanding children as 'adults-in-the-making'. Kjørholt et al. (2005) also claim that participatory methods tend to create oversimplified ideas and ambiguous views of what it is to listen to a child: Competence can be conceptualised as a static and inherent characteristic. It is therefore important to incorporate

interpretations of how children and humans in general (including adults) live their lives in mutual dependency. Even though we agree with this criticism, it is also important to remember that gaining insight into children's perspectives, or 'using a child perspective', is just as much about placing children in a bigger picture—it is not just about hearing what children say and ignoring adults, but instead we need to incorporate views and perspectives to everyone who can influence children's childhood(s) (Halldén, 2003). Hearing the children's perspectives about having a parent with T1D is also a good starting point for placing a focus on this under-researched topic, which should be further explored by, for example, including the perspectives of adults and health personnel.

We used four methods for exploring the children's views: a brainstorming exercise, an association exercise, a body map and diabetes supplies, and a diet exercise. All participatory methods used built on and complemented each other to explore the research questions 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. All methods were designed in a way that allowed the child to use his/her own words during the different tasks.

During *Brainstorming*, the child was asked: *What are your thoughts about the word diabetes?* The child was given 5 min to share all the words he or she could think of, which were written on post-it-notes. Thereafter, the child was asked what she/he thought or meant with the words written down. This exercise offered insight into the child's knowledge related to diabetes, and set the stage for further exercises.

In the *Association exercise*, the child was shown pictures of different diabetes supplies, like a blood glucose metre, an insulin pen- and an insulin syringe, and asked if he or she recognised any of the supplies. If the child recognised any of the equipment being presented, further questions were asked to explore the child's associations related to the equipment, for example: *Where have you seen it before? Do you know what it is used for?* The goal was to gain deeper insight into the child's knowledge and understanding of T1D and related medical equipment.

In the task called *Body map and diabetes supplies*, the child was handed a piece of paper containing the same pictures as in the association exercise, plus a body map. The child was asked to place lines between the body map and the pictures to illustrate how/where the equipment is used on the body. This exercise was performed to further explore the child's knowledge and understanding of T1D.

In the *Diet exercise*, the child was given two pictures: One of a smiley face, the other of a thinking face. The child was then given a stack of smaller food pictures and told 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). The child was told 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. The exercise offered insight into the children's knowledge about how diet affects a person with T1D.

After or during the activity-based methods, the first author asked the child questions from the semi-structured interview guide or other relevant follow-up questions based on the children's answers. She 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 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 min, 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 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, we (the authors) regularly met with each other. We also met during the period of the data collection, coding of data and discussed relevant findings. Thematic analysis was used to analyse the data set.

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

We started analysing the data after finishing the five first interviews. This was done to ensure high-quality data, and to facilitate potential adjustments in later interviews. We realised that some children had been confused in the association exercise, and made adjustments to the pictures presented in the exercise. We 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 12th interview, we 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. We 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 given an opportunity to read the interview guide during the recruitment process.

THE CHILDREN'S KNOWLEDGE ABOUT TYPE 1 DIABETES

By using child-friendly participatory methods, we 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, 6 years old, knew that the pen (Insulin syringe) in a picture of was 'a syringe for Insulin, because that thing in

the body (i.e. the pancreas) does not work'. Noah also said 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 5 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.

First author: "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, that is, 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, 7 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 needed it. Another boy named Oliver, 8 years, thought his mom needed the pump to know when she should eat sugar or other foods. When Ava, 7 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 asked what their thoughts were about the word diabetes during the first exercise. For example, Caroline, aged 5, answered 'but I do not know what it means', when she was 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 5-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 the first author asked Noah during the association exercise whether 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 whether the child was involved in his/her treatment.

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

By using participatory methods, we 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 Oliver was asked whether there was a difference between what he and what his mother could eat, he said:

Oliver: Big difference.

First author: 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.

First author: 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 said 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 the first author asked Lucas, 8 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 she 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 has to do with 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, 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 coach 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 said that some food 'gets into the blood', without explaining this in more detail. During the association exercise, when first author 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 she was 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 7-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.

First author: Ok, haha.

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

First author: 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:

First author: 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.

First author: Yes, ok.

Noah: With lots of sugar in it.

First author: 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, saying 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 5 years old, knew this and explained it 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.

First author: Yes...

Olivia: Then the blood sugar gets THIS HIGH!!

First author: 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 those who have 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.

HOW DO THEY COPE? THE CHILDREN'S FEELINGS, THOUGHTS AND WORRIES ABOUT T1D

None of the 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 first author asked Jacob, an 8-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 talking about different situations where his father had become ill due to low blood sugar levels.

The other boy, Oliver, said 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 the first author 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.

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

Oliver: (Nodding).

First author: 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 had to call 113 [911] if her mother became 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 wonder whether the worries experienced by two of the oldest children, Jacob and Oliver, are

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 7-year-old children more competent at worrying due to cognitive development.

DISCUSSION

In this study, we explored young children's (ages 5–8 years) experiences of having a parent with T1D and their understanding and knowledge about the disease. The aim of the study was to explore how younger children are affected by having a parent with T1D. The social studies of children and childhood emphasises the importance of conducting research with children, focusing on the children's own voices and perspectives (Brady et al., 2015). We therefore used child-friendly methods for exploring the children's views.

Our findings show that the children's knowledge about D1T was not age related and that some had more in-depth knowledge than others. We interpret this 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 taught them about T1D, the individual child's curiosity and interest, and the children's experiences with their parent's 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 (Curtis-Tyler, 2012; Rankin et al., 2017), that the children's ability to perform some of the self-management tasks in their diabetes treatment is not age related (Alderson et al., 2006; Koller et al., 2015; Rankin et al., 2017), and that experience is more important than age (Alderson et al., 2006; Brady, 2014). However, there are also studies of children with diabetes that have found age to be a mediating factor on knowledge about diabetes (Koller et al., 2015; Rankin et al., 2017). This indicates that age should not be ignored in future research on this topic.

Most importantly, our findings underlay that no universal childhood exists (Brady et al., 2015). Children are embodied health care actors who also will try to make sense of their parent's illness. When a parent suffers from a chronic illness like T1D, children should be understood as participants and agents who shape, and are shaped by, their environments. It is therefore important to study young children's views on equal footing as people in other age categories. That way we will gain more insight into the meaning and impact of health and illness on children's lives (Brady et al., 2015).

Our research also show that researchers need to keep an open mind when they conduct research with children (Ekra et al., 2015). Children often use different vocabulary than adults (Punch, 2002), which is important when choosing research methods for exploring children's views, as well as when analysing data. For example, only the two oldest children in our study expressed worries in relation to their parent's health due to their condition, while many of the younger children shared experiences of their parent having high or low blood sugar, but at the same time rejecting having experienced their parent as 'ill' through direct questions. This suggests that living with a parent with T1D is a part of the children's everyday life, which might lead to worries later on in life, as in the two older children in this study.

Our research can contribute to new insights into younger children's experiences of having a parent with T1D or other chronic conditions. Our study suggests that it is important to teach young children about the condition to limit (future) stress in their daily lives and foster coping strategies. In Norway, young children are not included in next-of-kin education unless the parents request it. Children's

experiences of having a parent with D1T will therefore depend on the child's experiences with the disease as well as the parent's level of teaching about it. In this sense, younger children with a parent with D1T can be considered as a 'minority group', being understood as dependents within the family, and they are also powerless in relation to relevant social and political structures in general (Mayall, 1998). Due to the obesity epidemic, we can also assume that more children will live with a parent with insulin-dependent diabetes in the future. We suggest that future studies should explore younger children's needs for information about diabetes, both at home and by health professionals (Jönsson et al., 2015) to prevent them from developing severe worries, and to limit stress in their daily, and future, lives (Grist & Field, 2012; Wichstrøm et al., 2017).

DATA SHARING STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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REFERENCES

- Alderson, P., Sutcliffe, K., & Curtis, K. (2006). Children as partners with adults in their medical care. *Archives of Disease in Childhood*, 91(4), 300–303. <https://doi.org/10.1136/adc.2005.079442>
- Aldridge, J. (2008). All work and no play? Understanding the needs of children with caring responsibilities. *Children & Society*, 22(4), 253–264. <https://doi.org/10.1111/j.1099-0860.2007.00094.x>
- Aldridge, J., & Becker, S. (1993). *Children who care: Inside the world of young carers.*: Department of Social Sciences, Loughborough University in association with Nottingham Association of Voluntary Organisations.
- Aldridge, J., & Becker, S. (2003). *Children caring for parents with mental illness: Perspectives of young carers, parents and professionals.*
- Brady, G. (2014). Children and ADHD: Seeking control within the constraints of diagnosis. *Children & Society*, 28(3), 218–230. <https://doi.org/10.1111/chso.12069>
- Brady, G., Lowe, P., & Olin Lauritzen, S. (2015). Connecting a sociology of childhood perspective with the study of child health, illness and wellbeing: Introduction. *Sociology of Health and Illness*, 37(2), 173–183. <https://doi.org/10.1111/1467-9566.12260>
- Clark, A. (2005). Ways of seeing: Using the Mosaic approach to listen to young children's perspectives. In A. Clark, P. Moss, & A. Kjørholt (Eds.), *Beyond listening: Children's perspectives on early childhood services* (pp. 29–51). Policy Press.
- Curtis-Tyler, K. (2012). Facilitating children's contributions in clinic? Findings from an in-depth qualitative study with children with Type 1 diabetes. *Diabetic Medicine*, 29(10), 1303–1310. <https://doi.org/10.1111/j.1464-5491.2012.03714.x>
- Dearden, C., & Becker, S. (2004). *Young carers in the UK: The 2004 report.* Retrieved from <https://hdl.handle.net/2134/627>
- Ekra, E. M. R., Korsvold, T., & Gjengedal, E. (2015). Characteristics of being hospitalized as a child with a new diagnosis of type 1 diabetes: A phenomenological study of children's past and present experiences. *BMC Nursing*, 14(1), 4. <https://doi.org/10.1186/s12912-014-0051-9>
- Gallacher, L.-A. & Gallagher, M. (2008). Methodological immaturity in childhood research? *Childhood*, 15(4), 499–516. <https://doi.org/10.1177/0907568208091672>

- Grist, R. M., & Field, A. P. (2012). The mediating effect of cognitive development on children's worry elaboration. *Journal of Behavior Therapy and Experimental Psychiatry*, 43(2), 801–807. <https://doi.org/10.1016/j.jbtep.2011.11.002>
- Guest, G., MacQueen, K. M., & Namey, E. E. (2012). *Applied thematic analysis*. SAGE Publications Inc.
- Halldén, G. (2003). Barnperspektiv som ideologiskt eller metodologiskt begrepp. *Pedagogisk Forskning*, 8(1–2), 12–23.
- Herrman, J. W. (2006). Children's and young adolescents' voices: Perceptions of the costs and rewards of diabetes and its treatment. *Journal of Pediatric Nursing*, 21(3), 211–221. <https://doi.org/10.1016/j.pedn.2005.07.012>
- International Diabetes Federation. (2020). *Type 1 diabetes*. Retrieved from <https://idf.org/aboutdiabetes/type-1-diabetes.html>
- James, A. (2001). Ethnography in the study of children and childhood. In P. Atkinson (Ed.), *Handbook of ethnography* (pp. 246–257). Sage Publications Ltd.
- James, A., & Prout, A. (1997). *Constructing and reconstructing childhood: Contemporary issues in the sociological study of childhood*. RoutledgeFalmer.
- Jaser, S. S., Whittemore, R., Ambrosino, J. M., Lindemann, E., & Grey, M. (2009). Coping and psychosocial adjustment in mothers of young children with type 1 diabetes. *Child Health Care*, 38(2), 91–106. <https://doi.org/10.1080/02739610902813229>
- Jenks, C. (1992). *The sociology of childhood: Essential readings*. Gregg Revivals.
- Jönsson, L., Lundqvist, P., Tibergh, I., & Hallström, I. (2015). Type 1 diabetes – Impact on children and parents at diagnosis and 1 year subsequent to the child's diagnosis. *Scandinavian Journal of Caring Sciences*, 29(1), 126–135.
- Katsarou, A., Gudbjörnsdóttir, S., Rawshani, A., Dabelea, D., Bonifacio, E., Anderson, B. J., Jacobsen, Laura M., Schatz, Desmond A., & Lernmark, Å. (2017). Type 1 diabetes mellitus. *Nature Review Disease Primers*, 3(1), <https://doi.org/10.1038/nrdp.2017.16>
- Kavanaugh, M. S., Noh, H., & Studer, L. (2015). “It'd be nice if someone asked me how I was doing. Like, cause I will have an answer”. Exploring support needs of young carers of a parent with Huntington's disease. *Vulnerable Children and Youth Studies*, 10(1), 12–25.
- Kingod, N., & Grabowski, D. (2020). In a vigilant state of chronic disruption: How parents with a young child with type 1 diabetes negotiate events and moments of uncertainty. *Sociology of Health and Illness*, 42(6), 1473–1487. <https://doi.org/10.1111/1467-9566.13123>
- Kjørholt, A., Moss, P., & Og Clark, A. (2005). Beyond listening: Future prospects. In A. Clark, A. Kjørholt, & P. Moss (Eds.), *Beyond listening: Children's perspectives on early childhood services* (pp. 175–187). Policy Press.
- Koller, D., Khan, N., & Barrett, S. (2015). Pediatric perspectives on diabetes self-care: A process of achieving acceptance. *Qualitative Health Research*, 25(2), 264–275. <https://doi.org/10.1177/1049732314551057>
- Laroche, H. H., Davis, M. M., Forman, J., Palmisano, G., Reisinger, H. S., Tannas, C., Spencer, M., & Heisler, M. (2009). Children's roles in parents' diabetes self-management. *American Journal of Preventive Medicine*, 37(6 Suppl 1), S251–261. <https://doi.org/10.1016/j.amepre.2009.08.003>
- Mayall, B. (1998). Towards a sociology of child health. *Sociology of Health and Illness*, 20(3), 269–288. <https://doi.org/10.1111/1467-9566.00102>
- Moss, P., Clark, A., & Kjørholt, T. (2005). Introduction. In A. Clark, A. Kjørholt, & P. Og Moss (Eds.), *Beyond listening: Children's perspectives on early childhood services* (pp. 1–16). Policy Press.
- Nilsen, R. (2003). Barn og kvinner, barndom og kjønn. En barneforskners blikk på to forskningsfelt. *Kvinneforskning*, 3, 94–115.
- Pettus, J., & Von Herrath, M. (2018). The shifting paradigm of a “cure” for type 1 diabetes: Is technology replacing immune-based therapies? *Acta Diabetologica*, 55, 117–120. <https://doi.org/10.1007/s00592-017-1069-8>
- Punch, S. (2002). Research with children: The same or different from research with adults? *Childhood*, 9(3), 321–341. <https://doi.org/10.1177/0907568202009003005>
- Rankin, D., Harden, J., Jepson, R., & Lawton, J. (2017). Children's experiences of managing Type 1 diabetes in everyday life: A thematic synthesis of qualitative studies. *Diabetic Medicine*, 34(8), 1050–1060. <https://doi.org/10.1111/dme.13362>
- Sieh, D. S., Meijer, A. M., Oort, F. J., Visser-Meily, J. M. A., & Van der Leij, D. A. V. (2010). Problem behavior in children of chronically ill parents: A meta-analysis. *Clinical Child and Family Psychology Review*, 13(4), 384–397. <https://doi.org/10.1007/s10567-010-0074-z>
- Tisdall, E., & Puch, S. (2012). Not so ‘new’? Looking critically at childhood studies. *Children's Geographies*, 10(3), 249–264. <https://doi.org/10.1080/14733285.2012.693376>

- Trondsen, M. V. (2012). Living with a mentally ill parent: Exploring adolescents' experiences and perspectives. *Qualitative Health Research*, 22(2), 174–188. <https://doi.org/10.1177/1049732311420736>
- Tyler, K. (2009). *Levers and barriers to patient-centred care with school-age children living with long-term illness in multi-cultural settings: Type 1 diabetes as a case study*. : City University.
- Webster, M. (2018). Siblings' caring roles in families with a child with epilepsy. *Sociology of Health and Illness*, 40(1), 204–217. <https://doi.org/10.1111/1467-9566.12627>
- WHO. (2016). *Global report on diabetes*. World Health Organization.
- Wichstrøm, L., Belsky, J., & Steinsbekk, S. (2017). Homotypic and heterotypic continuity of symptoms of psychiatric disorders from age 4 to 10 years: A dynamic panel model. *Journal of Child Psychology and Psychiatry*, 58(11), 1239–1247. <https://doi.org/10.1111/jcpp.12754>
- WMA General Assembly. (1964). *Declaration of Helsinki – Ethical principles for medical research involving human subjects*. Retrieved from <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>
- Wyness, M. (2012). Children's participation and intergenerational dialogue: Bringing adults back into the analysis. *Childhood*, 20(4), 429–442.

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