“The Logic of Care” – Parents’ experiences of the education process when a child is newly diagnosed with type 1 diabetes

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Abstract

Background

The number of new cases of type 1 diabetes mellitus (T1DM) has increased substantially in recent years and it is one of the most common long-term endocrine disorders in childhood. In Sweden the child and family are hospitalized, in accordance with the national guidelines, for one to two weeks at diagnosis. The purpose of this study was to explore the parents’ experiences, in the light of a theoretical framework, of the educational process when their child is newly diagnosed with T1DM.

Methods

Qualitative interviews were performed, in the south western part of Sweden, with ten mothers and eight fathers of children diagnosed with T1DM three to six months after they had received the diagnosis. The interviews were analysed using deductive content analysis.

Results

The results show that almost all parents had experienced the education process as satisfying. However, most parents stated that more teaching was needed concerning: how to live with diabetes in the individual families’ everyday life instead of a teaching based on a fixed schedule, parents centered teaching instead of cramming of knowledge, time for grief and shock, less emphasize on what to do and more on why. The routines learned at the hospital made the parents’ efforts at being good parents managing the child’s disease and continuing normal family life a difficult task.
Conclusions
In order to optimize the educational process for families with children newly diagnosed with T1DM it might be useful to have a theoretical framework illuminate on the process and make it more understandable for the involved professionals. Good care is about keeping a balance when the care interferes in the patients’ values and influences every part of their lives. However, more research is needed before we can tell whether or not it is constructive to use this theory.

Key words
Diabetes education, children, parents, qualitative research, type 1 diabetes

Background
More than 346 million people worldwide have diabetes [1] and the number of new cases in childhood-onset type 1 diabetes mellitus (T1DM) has increased substantially in recent years, particularly in younger children [2]. In Scandinavia about 94 000 children have been diagnosed with T1DM and it is predicted that in 2020 there will be approximately 160 000 cases [3]. When children are diagnosed with T1DM it is the parents who have to be responsible for the daily management of the child’s disease. Despite this fact the children, depending on their age, also have to understand the conditions of diabetes and how to manage them [4]. Therefore, it is important that patients and parents are actively involved in the care [5]. The aim of diabetes care is to maintain normal blood glucose levels to allow normal growth and development of the child [6]. Given the multiple medical and behavioural demands inherent in the contemporary management of diabetes, for example checking blood glucose levels, administering insulin injections and having control over eating and activity, it is evident that many parents experience
a range of emotional responses with anxiety as the most consistent symptom [7]. It is important that professionals are aware of the parents’ vulnerability at the time of diagnosis [8].

The educational process starts immediately after the child is diagnosed with T1DM. Most often a multi-professional team, with special knowledge of children, i.e. a doctor specialized in paediatric diabetes (DSP), a paediatric diabetes specialist nurse (PDSN), a dietician, a social worker and a psychologist [9], is responsible for the education process. The Swedish education process is based on national guidelines [10] and follows the recommendation of the International Society for Paediatric and Adolescent Diabetes (ISPAD) with regard to the management of T1DM in children and young people [9]. This includes a checklist, which in detail guides the formal content of the knowledge and skills that the family needs in order to be able to cope [11]. During the educational process, which in Sweden takes place in hospital for a period of one to two weeks, the professionals prepare the child and family. The family’s ability to manage the self-care is tested by granting them leave from the hospital; first for some hours and then for a day and a night before discharge [12].

Theoretical framework
The theoretical framework is based on the philosophical theory The Logic of Care by Annemarie Mol [13] from the Netherlands. Mol argues that good care has little to do with “patient choice” and concludes that good care is something that grows out of collaborative and continuing attempts to attune knowledge and technologies to diseased bodies and complex lives.
The standard of individual choice in health care, as it is advocated in health care laws in Sweden and Europe today, was to get away from the previously dominant view that when a patient meets a doctor, the doctor observe, investigate and prescribe different tests without the patient’s voice heard. To be able to make critical choices for their lives when being affected by a disease patients’ need to be heard and respected as subjects. Mol [13] argues that if a person has just been diagnosed with for example diabetes, it is most likely that the person is scared and confused and in that situation would like health care staff make choices for them. In this situation the patient need to be involved in the practical measure that the therapy includes. This is a world infused with what Mol calls the logic of choice. In care practices patients are not passive i.e. patients are active, not as subjects of choice but as the subjects of all kinds of activities.

The logic of care concentrates on what kind of activities the patient is engaged in. The professionals have to open up and share the crucial substantive questions with the patient i.e. how to live well, what to die from depending on the disease involved [13] in order to shape good life despite illness.

Living with diabetes requires sensitivity and flexibility. The patient has to be aware of what is happening in the body and respond to what happens as well as be adaptable. To achieve this requires sound relationship with the DSP and PDSN as well as with the patient’s surroundings. Such a relationship with the professionals and with the sick body is by Mol [13] called patientism i.e. trying to establish living with a disease, rather than normality as the standard. Patientism seeks ways to be kind to the body, to allow the body to exist compared to healthy people who do not have to worry about their body [13]. In the logic of care is patientism that the
professionals motivate the patient to recognize their body’s signals for wellbeing and malaise. In the logic of choice is patientism that the professionals get into every individual patient’s lifestyle, values and sick body’s reactions i.e. to jointly explore ways to achieve a good life despite a fragile body.

The DSP and the PDSN are experts in the diabetes disease pathogenesis and its treatment. What happens in the body when the body is affected by diabetes is something that the patient must understand as well as how diabetes is treated generally. For example, diabetes patients have to be able to inject their own insulin, measure their own blood glucose level, and count the carbohydrates they eat, calibrate their exercise and take care of themselves in many other ways [13]. It is the patient who must control the teaching of diabetes and how the treatment will be implemented. This calls Mol [13] *doctoring*. Doctoring is in the logic of care that the professionals show the patient a great commitment by paying attention to the patient’s emotional reactions. It also about being inventive so that teaching fits the patient and his or her life. This requires endurance and understanding of the difficulties that the patients may feel that they have in daily life with diabetes. In the logic of choice is doctoring that teaching be fully adapted to patient needs i.e. patients are called to manage their doctors. “Attending to the patients’ experiences would allow the diabetes team to fine-tune their activities better. It is a matter of trying things out and of being willing to revisit what has been done before, i.e. try again, adjust, improve” [13] (p. 56).

The professionals adapt their knowledge to the patient’s real life. This is what Mol [13] calls *shared doctoring*. In the logic of choice shared doctoring requires that all concerned i.e. members of the diabetes team and the patient is taking each other's contributions seriously and
simultaneously adapt to what the body, blood glucose devices, diet and other relevant stuff show.

In the logic of care shared doctoring is that all involved in the care must respect each other's experience of the disease, while being committed and creative as well as careful in their explorations. By taking advantage of all involved persons strengths and limitations when it comes to understanding how all these variables affect the body, all concerned must be willing to change their perceptions to jointly search for what can be done to improve the patient’s life with diabetes.

According to Mol [13] the patient’s encounter with the diabetes team is that the patient is not a passive object for measurement of blood glucose and treatment. Activity characterizes the patient. In the logic of care are the body and the patient active, i.e. the body is active in that the patient may be thinking that he/she is thirsty and drinks a lot. The doctor asks how much and the patient may respond four liters/day and interprets it as the symptoms of diabetes and to diagnose the patient is active by giving blood and urine for tests. The patient is also active by wanting to know the values of the tests and the doctor verify the diagnosis. In the logic of choice cooperate the patient with the diabetes team (if not having diabetes coma) by observing what is done, ask, listen and perform the care during the supervision of the PDSN. The patient active learn from the diabetes team. After a few days the patient insists on performing self-care and the PDSN is supporting the patient’s caring activities.

As a body with diabetes does not silently regulate its own sugar uptake, the patient has to actively balance the energy in the food with the energy she/he use up and the amount of insulin the patient inject. Taking care of oneself is a physical competence: it requires to educates and
train the own body. The patient may recognize the early warning signs of upcoming hypos, not by transcending one’s body but by inhabiting it. Such intro-sensing is an intriguing skill that may be trained. This is what Mol [13] calls sensitivity. In the logic of care is sensitivity about to make the patient aware of understanding how she/he can appreciate the blood glucose value by learning how the body works at low blood glucose such as dizziness, irritation or anything else. In the logic of choice is sensitivity about finding out how to measure so that technologies, habits, etc. have to be adjusted to the patient’s life [13]. “There should be space for sadness, but not too much. A doctor should offer consolation, but also encouragement. And while suffering must be recognized as bad, the disease must simultaneously be accepted as something that needs to be dealt with in one way or another as life goes on” [13] (p. 43).

To have diabetes is that the person must learn to become a different person, in Mol’s theory [13] called individuation. In the logic of care is it about submit personal courage to learn to be an outlier. In the logic of care the PDSN has an important role in supporting the diabetic person, and encourages and praise when the person stands up for her/his own life and the dietician may be the one who gives support to give up the diet that is not necessary. It is about to take the patient’s environment seriously i.e. to reach the goal that the family and friends care about the person with diabetes concerning diet and how meals should be planned. In the logic of choice it is about that the person in time gradually gets used to be outliers by taking the insulin without hiding, to abstain from desserts with a good feeling etc. It is to choose to participate in the social life despite the disease.
The purpose of this study was to explore parents’ experiences of the educational process, in the light of Mol’s philosophical theory “The logic of care”, when their child is newly diagnosed with T1DM.

**Methods**

**Study design**

A qualitative descriptive method was used to achieve a deeper understanding of the educational process during the initial stage after a child is diagnosed with T1DM. The data was collected through interviews which were analysed with a deductive content analysis [14, 15].

**Setting**

The study was conducted in the south western part of Sweden including three paediatric departments. Each paediatric department cared for about 20-30 children, newly diagnosed for T1DM each year. The number of children from 0-18 years in the catchment area of each department was about 55 000-70 000. At each department the diabetes team consisted of a DSP, a PDSN, a dietician, a social worker and a psychologist. The DSP and the PDSN have the main contacts with the child and the family, the dietician has appointments with the families on a regular basis and the psychologist and social worker have appointments on demand during the hospital stay.

**Participant recruitment**

Inclusion criteria were parents to children, three to 16 years, who had been diagnosed with T1DM within the last three to six months. The PDSN at each hospital who recruited the parents contacted them and gave them both verbal and written information about the study as well as a
form for informed consent. Fourteen families were asked to participate and 10 agreed to participate. Parents who agreed to participate sent the informed consent to the PDSN. Subsequently the informed consents were handed over to the first author (LJ) who in turn contacted the families. Time and place of each interview was determined in consultation with the parents. The study was conducted according to the Helsinki declaration [16]; including information about the purpose of the study, time commitment, confidentiality, the voluntariness, and the right to discontinue participation at any time, and informed written consent was obtained. The study was approved by the Research Ethics Committee of the Medical Faculty, Lund University, Sweden (2007/305, 2009/371). Permission was obtained from the chief physician at all departments involved.

**Conducting the interviews**

In total 18 individuals were interviewed including 16 cohabiting parents, one mother not living with the father of the child, and one single mother. Demographics of the participating parents and their family are shown in Table 1. The interviews started with an open ended question, “Please, narrate your experiences of the care during hospitalization when your child was diagnosed with type 1 diabetes”. An interview guide was developed, including six areas (Table 2), which was used in case the subjects were not brought up by the parents in the interview. The interviews were conducted between the spring and autumn of 2010 by the first and the last authors. Seventeen interviews took place in the homes of the families and one at the parent’s place of work according to the parent’s preferences. If both parents accepted to be interviewed at the same time, the interviews were carried out at the same time but in separate rooms, by the first author (LJ) and the third author (AL). The authors shifted between interviewing mothers and
fathers. Each interview lasted for between 45 and 90 minutes. All interviews were transcribed verbatim by the first author (two interviews) and by a secretary.

**Analysis**

In a first step the transcripts were read by all three authors. In a second step all text that appeared to represent information and teaching about T1DM as well as emotional reactions was highlighted to make sure that all possible occurrences of the phenomenon, the educational process when a child in the family was newly diagnosed with T1DM, were captured [17]. The third step in the analysis included each interview being divided into units of meaning, i.e. sentences that were related to the same meaning unit [15]. In the fourth step each meaning unit was condensed to shorten the sentences but still save the core [15]. Then, in a fifth step, each condensed meaning unit was labelled according to specific codes; in this study patientism, doctoring, shared doctoring, activity, sensitivity and individuation, according to the theoretical framework, are used [13]. The encoded texts from each interview were thereafter placed under each other and read repeatedly to make sure that the content was true to the intentions in the code content. After this the text was summarized under each code and all interviews were read once again in order to confirm that all text relevant for the purpose was included. The different steps in the analysis were performed first separately by the first and the third author and thereafter discussed and reflected upon until consensus was reached. Finally, all three authors reflected upon and discussed the results by going back and forth between the interview text and the predetermined codes until consensus was obtained.
Results
The results are described according to Logic of care; patientism, doctoring, shared doctoring, activity, sensitivity and individuation.

Patientism
The parents felt that they were in shock and had practically no previous experience of T1DM when the child was diagnosed with diabetes. A diabetes team consisting of a DSP, a PDSN, a dietician, a social worker and psychologist often introduced themselves during the family's first days in the hospital and gave the family a planning time table for the hospital stay. This rapid initiation of therapy and appointments with the diabetes team the family experienced both as confusing and as a security. The parents were put on sick-list for about a month after diagnosis. Both parents were recommended to stay at the hospital with their child during the planned admission i.e. 10-14 days and depending on the child’s age and status. The parents described that they usually stayed both at the hospital in the daytime, but often only one parent stayed overnight.

When a preschool child protested against taking blood glucose or insulin injections the parents experienced that the professionals tried to cooperate with the child in various ways. Sometimes, the child did not accept, but the professional then set a limit and said that, this must be done and proceeded to inject the child.

“Because it was a period when she refused to [go with the insulin injections] …They tried to coax a while but then it was stopped, and it was good because I learned that this is the line as well, now you just do it” (2, mother).
Some families had experienced that at times the professionals were not responsive enough to the child’s opposition towards insulin injections. The child would communicate via its parents and the professionals gave in after a while and left the room whereupon the child did not want to speak or respond to the professionals any more. In this situation one mother took a decision together with the child to manage the injection by themselves in spite of having no training in giving injections but having watched the professional’s procedure. The mother and the child did it and all times afterwards. Both the family and the professionals were satisfied with the outcome.

**Doctoring**

The parents experienced that they had received a fantastic reception and care when entering the paediatric hospital. The professionals took care of the child directly and the parents saw them as being knowledgeable and calm. Being informed about the good treatment that exists today and about the parents not having been able to prevent their child from getting T1DM was very important as they immediately got feelings of guilt and wondered if the onset would have been possible to avoid.

“The DSP and the PDSN reassured us [parent and child] by saying that we will know everything before going home, which had a calming effect” (3, mother).

The parents had the impression, when encountering the DSP and PDSN that they had a great deal of knowledge and extensive experience of diabetes care as well as a strong engagement in
teaching the parents to be able to take care of their child’s body affected with diabetes. At first the DSP lectured on diabetes and its treatment and after that the PDSN took over with a similar content, but in a more practical way. The DSP and the PDSN overlapped when it came to knowledge about T1DM, which was appreciated by the families, as it became a form of rehearsal. The families who did not receive this commitment and confirmation experienced that they never understood the disease during the hospitalization.

The parents felt that the DSP and the PDSN had taught them about what had happened in the child's body and what the body needed in order to be able to function in the future. The teaching continued step by step about how diet, activity and insulin affected the child's body. Both children and parents were recommended to be present, but sometimes the child, depending on his/her age, went to play-therapy. When the child was present, the professionals turned to the child with the teaching and also emphasized, with eye contact, the seriousness of having T1DM. This presentation was experienced by the parents as a support in getting the teenagers in particular to understand the seriousness of the situation.

”... I think she realized pretty quickly at the first appointment with the doctor when he explained to her that this is a dangerous disease... she understood that this [the disease] was nothing that she lost the next week but would live with it” (8, mother).

The education was experienced as being intense. The parents felt it was a cramming of knowledge, especially when the child was not present. The parents accepted this and they wanted to know as much as possible about the disease. A few parents experienced that they never got to
know the diabetes team and found no structure in the learning during the hospitalisation. They became frustrated because they did not understand the diabetes or the caring at all. They were full of questions but could not formulate them. Many experienced the learning as being about what to do but not why leading to that they experienced that they overprotected the child after discharge. It was not until three month after discharge when the family had an appointment with the diabetes team, that they got an understanding of the diabetes and the care.

There was a wish from the parents that the professionals would have given more active advice on how to live with diabetes at home. All the parents were struggling to be good parents; both in terms of managing the child's diabetes but also in terms of seeing to that the child's life would continue to be as normal as possible despite the diabetes.

“Sometimes it may feel easier and safer to say no [relating to food and compromise on time], but it’s all about the child’s life not about our [the parents] life” (7, mother).

**Shared doctoring**

The professionals were perceived to have a lot of patience and an open mind when the parents found it difficult to take in and understand the disease and care. Parents highlighted that the DSP often drew cartoons that made it easier to understand the teaching. All the families had received brochures and a book about T1DM to read on their own. In spite of intense days, there was, nonetheless, time for reflection in which parents discussed among themselves.
Calculating the insulin dose was perceived as difficult but some families were offered a template to facilitate the decision about how much insulin was needed in relation to the blood glucose value. Blood glucose was measured before and after every meal and at night. The same adherence to diet and insulin doses as during the hospitalization was followed during the one to three months after discharge. Gradually the professionals left the issue of how much insulin the child should have in relation to blood glucose level and diet. The parents experienced that it was a positive guidance that allowed the family to gradually grow into self-care.

Great emphasis was placed on the symptoms of hypoglycaemia but teaching about what to do in the event of hyperglycaemia was limited. The parents experienced troubles with hyperglycaemia often arose in the evenings or during the night after discharge due to a lack of knowledge. Many children had sport activities and the parents appreciated the teaching and advice about what to consider before and after sporting. The appointment with the dietician was based on the child’s present diet, modified so it would be appropriate diet for the child after the diagnosis. There was disagreement on the dietician teaching efforts but mostly the parents appreciated diet advices. The appointment with the dietician was based on the child’s present diet that was modified so it would be appropriate for the child after the diagnosis. There was some discrepancy regarding the dietician’s teaching efforts but, on the whole, the parents appreciated dietetic advice.

“…Dieticians …they are so far from reality and are so careless with food. They have their learning as well, eh … But it’s good, you should aim high” (4, father).
Sometimes the children could choose a blood glucose meter and insulin pen while others only had the opportunity of choosing the colour of the blood glucose meter. Some of the parents thought it was safest to choose the same blood glucose meter and pen that had been used at the hospital. The parents described that the choice of insulin was not discussed with the parents.

The parents experienced that compassion and caring permeated the entire hospital stay. It was encouraging to both parents that they were on sick leave and were at the hospital during daytime so they could support each other both in the medical caring and in their sorrow. Parents and their children a very much appreciated the play-therapy and the hospital school. It was a way of forgetting the disease and the misery they felt for a while.

After having been in hospital for 10 to 14 days, the parents experienced that the longed to go home; even if they did not feel they had the care completely under control they felt ready for discharge. The parents were informed that they could phone the DSP or PDSN if there was any problem.

**Activity**

Prior to diagnosis, the majority of parents had presented non-specific complaints such as enuresis or weight loss in the child. Immediately the doctor suspected that the child had T1DM, and referred the family to the nearest paediatric hospital. At the hospital the diagnosis was confirmed with new blood samples and the first information about the disease were given.
The parents experienced that the professionals at the ward and the PDSN taught them and their children to take care of the practical stages such as taking blood glucose as well as giving and/or taking insulin injections. To begin with, the professionals showed them how to do it and the child and their parents watched. After the family had trained on giving injections using an orange, the parents pricked themselves in the finger to take blood glucose and injected sodium (NaCl) into their stomachs. Some parents pointed out that the professionals never asked if they were afraid of injections, they just assumed that the parents would be able to inject themselves.

“Today it’s dad’s turn to try and inject himself in the stomach [said the PDSN]... Well, you couldn’t back down so it was just to go ahead and do it and it was all right”

(5, father).

The parents experienced that the professionals gave the injection to the children until such time as they either felt ready to inject themselves or their parents were ready to inject them after some boosting and encouragement. The children either injected themselves immediately or it could take days or weeks until the child felt ready to inject the insulin themselves. In the case of the preschool children it was often the parents who took the blood glucose and gave the insulin injection to the child.

The parents described that before discharge parents and children over 10 years of age had a form of examination of their acquired knowledge and skills, answering a questionnaire and discussing the answers with the PDSN. Another way for evaluation was that the PDSN asked what the
family would do the next few days after discharge and how they thought they would do in various situations that might arise.

**Sensitivity**

When a young teenager objected to taking his/her insulin injection the professionals would try to talk him/her to terms by asking: “What happens in your body if you don’t receive insulin?” This treatment was appreciated by the parents as a good approach and a great way of dealing with young people.

The teaching included information that the blood glucose levels should correspond to certain values, even though some parents noticed that their child got hypoglycaemia at other values.

> “Hypoglycaemia did not come until ... he can be low down on the three ... without having a hypo ... he has even made measurements for three with no feeling of hypo. It took some time for him to believe it was a difference between being low and having hypo ...” (6, mother).

During the first days the families felt that they were not allowed to leave the ward. Gradually, they were encouraged to stay in the hospital environment for brief periods. In a dialogue with the diabetes team it was decided when it was time to go on a short leave. For some families, this might take place early on due to some kind of celebration, such as breaking-up day or midsummer. Such short leaves the parents experienced were affirmed by the DSP and the PDSN and were well planned together with the family.
The diagnosis came as a shock and the parents experienced that they were saddened by the news that their child had got a chronic disease. At the hospital, the parents experienced that they were living in the moment as they wanted to learn to take care of the sick child's body but they felt sad inside. They had to keep a “brave” face for their children and they only let the tears come when they were alone. The parents expressed that it was disappointing that there was no time for grief and shock. The social worker and psychologist included in the diabetes team had introduced themselves to most of the families but no specific appointments were planned except that they all met the social worker for a discussion of social benefits regarding the child’s chronic illness. Some parents did not feel ready to talk with a psychologist, while others lacked the opportunity.

“I felt like we put our problems in their hands and they took care of them in a nice way… it’s not just facts and figures but there’s also a concern” (6, father).

**Individuation**

Parents were quick to realise that the care of the child's diabetes required a substantial structure in daily life but the willingness to learn about how the child's body functioned was immediately apparent. Even so, the parents experienced a sorrow that life could not be the same as before, they could no longer do things spontaneously in their family as everything has to be planned in advanced.

“I asked the PDSN about how well I have to manage here disease. Must it be to 120% or if it was okay with 80% sometimes. The PDSN replied that it was okay with 80% sometimes. It was a relief” (7, mother).
The parents described that the dietician took the family to a grocery store and the family told the
dietician about what kinds of food they used to buy. The dietician then gave them alternatives
they could choose from and guided them as to what to think about when shopping. Several of the
children had previously been drinking a lot of milk and had eaten white bread but the change of
diet was mostly uncomplicated when the dietician and the family, through discussions, found
alternatives.

The PDSN had informed the teachers and pupils at the child's preschool or school about T1DM
and what it means to have this disease. Furthermore, she informed them about what teachers and
pupils could help the child with both in everyday life and when an emergency occurs such as
hypoglycaemia. The parents also described that often even relatives received basic information
about T1DM.

"It is important that those who take care of her in school know what to do. She can inject the
insulin by herself, but you have to make sure she puts the pen on the correct insulin value… She's
only seven years old…" (8, father).

The parents experienced that they brought the routines they had learned at the hospital back
home. It was important to keep the times and procedures with regards to diet, insulin and
different activities. All routines had an influence on family life and made a big change in their
social situation. Even so, the parents experienced sorrow that life could not be the same as
before, they could no longer do things spontaneously in their family as everything would have to be planned in advance.

“It is very focused on times ... when we had guests in the evening and they called and said they will be 30 minutes late, you had to say it was okay, but it meant that our daughter had to eat before the guests arrived ... so it affects the social side very much” (6, father).

Discussion
This study has been conducted to explore parents’ experiences of the education process when their child is newly diagnosed with T1DM performing the analysis by using a theoretical framework, “The logic of care” by Mol [13].

The reason for choosing to apply the Mol’s [13] theory to the parents’ experiences of the education process when their child is diagnosed with T1DM is that the theory suggests that the professionals must be sensitive to children’s and families’ values so that normative facts relate to the families’ lives. The challenge in the educational process according to Mol [13] is about that the professionals, the parents and the child together, at the first meetings with each other, must be prepared to share experiences, knowledge, assumptions about the disease and the situation that the family is in. The professionals have to find a common language that everyone feels comfortable with i.e. the professionals and the children and their families support each other. Education is crafted for a more decent way of living with or in reality.

The parents included in the study were selected by the PDSN after their children were diagnosed with T1DM three to six month after diagnosis. The majority of parents were Swedes, living in
private houses, in both large and small towns and most of them were married or cohabiting. This implies geographical and cultural constraints and it is known that socioeconomic status and chronic disease can affect parenting [18]. Qualitative studies produce rich and detailed information, on a small number of cases, the value of which lies in the insights that can only be obtained by detailed work [19]. Both parents are interviewed separately as studies show that there are different opinions about fathers’ responsibilities for children with diabetes [20-22]. However, in our study both parents seemed to be very engaged in the education process and supported each other.

In the interviews parents were first asked to narrate their own unique experience. If some areas needed to be explored more, questions and follow up questions were asked in accordance with the interview guide [23]. The interview guide was developed after an interview study among paediatric diabetes teams with a focus on the initial education process at hospital after a child is newly diagnosed with T1DM [12]. There is a risk that an inconvenient time and setting might affect the content of the interview [19]. Therefore, all the interviews were conducted at the families' convenience and, in general, in their home, as we hoped that this would allow them to feel free and comfortable.

Mol’s theory [13] has been published relatively recently and has, to our knowledge, not been used in research so far. We do not know if it is practically applicable in the care of children newly diagnosed with T1DM as it emanates from an adult perspective and outpatient care. Some self-criticism is therefore justified as to how we have interpreted the application of the theory.
The aim of the theory is to avoid unmarked normality and rather seek to contribute to theoretical repertoires that no longer marginalize, but instead face the disease. It is obvious that the DSP and the PDSN mostly follow the guidelines for diabetes education of children and young people as described by ISPAD [9] at diagnosis. This is in line with the results from a previously conducted interview study with the professionals in the paediatric diabetes team [12]. The guidelines emphasize, just as Mol [13], that professionals should learn to incorporate and deliver the education using behavioural approaches which are learner-centred [24]. The educational model for diabetes education is based on the view that the effects are most potent when integrated into routine care, when parents are involved, when empowerment principles and problem-solving are involved, when goal setting is performed and self-efficacy is promoted [25]. The five-step empowerment model which has been shown to be effective and evidence-based in previous studies [24, 26, 27] emphasizing that the patient will be involved in all of the care and reflecting upon how the treatment fits in with the patient’s life is, to a great extent, in concordance with Mol’s theory [13] concerning her emphasis on the patient’s values in the education process.

Almost all parents felt that they were in good hands and surrendered themselves and their sick children. This can be interpreted as an obstacle to patientism because parents belittle themselves by their strong emotional experience when it turns out that they do not understand anything about the disease. This is not in concordance with the logic of care but a phenomenon that occurs in paediatrics [28] that leads to difficulties for parents who become overpowered by their feelings and thereby no longer have the capability to express their own will. Thereby they may lose their dignity towards themselves and the professionals and their child. According to Mol [13], in order to avoid this phenomenon, the professional would start the education process by
asking the parents what they know about diabetes or if they know someone who has diabetes and to have this as a starting point in teaching. Parents felt strongly that they could rely on the DSP and the PDSN i.e. patientism, in receiving attention and became conscious of their future responsibility for the illness. This is also shown in Wennick and Hallström [29] who interviewed 23 parents to children newly diagnosed with T1DM. In their study, as well as in the present study, most parents were satisfied with the education concerning technical management in the same way as is shown in Challener and Davies [30] who stated that parents appreciate the training for injection technique, blood testing and diet management i.e. doctoring.

In the logic of care and the logic of choice the professionals should, after teaching the parents what the diabetes does to the child’s body and which medical treatment is necessary, let the parents come to turns with the disease by themselves based on the activities the parents and the child are invited to participate in [13]. However, in our study the parents’ own reflections i.e. sensitivity, were not always asked for, i.e. values on how they planned to cope with everyday life with diabetes. On the other hand, maybe the parents did not ask for time for reflections together with the professionals and therefore the professionals felt that there was no need to address this issue. If the theory works the parents are supposed to bring to the fore their concerns of their everyday life in an open and honest manner and, together with the professionals find a better lifestyle for the family i.e. shared doctoring. But as experienced by some parents it could take some time for parents both to be aware of the concerns and to be able to formulate them. Sometimes it took several months and it was not until the meeting at the out-patient clinic that an honest relationship was established.
Although the parents in our study do not mention that they seek control in their lives by following the hospital routines we can imagine that they are struggling for control. A life with diabetes can never lead to full control because life changes all the time and the most important prerequisite for living a good life with diabetes is to listen to the signals from the child’s sick body [13]. During the education process it does not seem to be the child’s body signals that are in focus. For example, all parents get the same target of low and high blood sugar levels irrespective of at what level the child gets hypoglycaemia. Based on the theory, Mol insists that doctoring is all about making a tailor-made assessment for each individual; in this case it would be deciding the blood sugar value that is tailor-made for each child according to the signals of the body. The parents’ own participation in the various training elements highlighted by Mol [13] is not awaited instead the parents experience was that there is a plan to be followed. Professionals tick off various moments as they are performed on the checklist e.g. leaflets and a book are handed over to the parents even if they are not discussed with them. From the parents experience neither is the day or time for training injections discussed but is decided by the professional.

Being on leave is appreciated as it is a way to try out self-care. However, the professionals do not always take the opportunity to ask parents how things went unless the parents ask for an evaluation. There are good examples of negotiations; when the dietician accompanies the parents to the grocery and have discussions based on the parents’ shopping lists i.e. shared doctoring and individuation. Other examples are when the families may choose blood glucose meters among those that are presented by the professionals i.e. shared doctoring. The parents also spontaneously take the opportunity to assume their own values to solve problems, for example,
when the child refuses to be given insulin injections and the mother and the child manage it without interference of the professionals i.e. patientism.

The parents felt sorrow when their child was diagnosed with T1DM, but during the hospitalization there was no time for grief. So the parents learn about the disease and keep the sadness inside. According to Mol [13] the sorrow has to be put aside to focus on how to learn about the sick body. However, other studies suggest that the professionals not only assess the child’s wellbeing but also look for symptoms of anxiety among parents especially during the first months after diagnosis [8, 31].

It is found that parents coming home with children newly diagnosed with T1DM have difficulties in adapting the regime, and an enhanced need to stay in control, to their ordinary life [29, 32, 33]. In our study the families had similar experiences and they continued with the rules learned at hospital at home without adapting the rules to the family lifestyle. This may, according to Mol [13] mean that the family themselves have made this choice possibly without understanding how much it affects the family and therefore feel a limitation in that situation.

**Conclusions**
The finding is in concordance with “The Logic of Care” in that the professional is felt to be knowledgeable and experienced by the parents, and committed to the family, inspiring trust and confidence in that their child is in good hands (patientism). The theory also stresses that the relationship between parents and professionals is so acquiescent that parents spontaneously talk
about their mistakes and problems in everyday life with the professional, which all parents in the study feel comfortable with especially after discharge (shared doctoring).

What is not in compliance with “The Logic of Care” is that the acquisition of knowledge and skills is largely derived from a structured programme that controls when and what is to be learned day by day. The parents are more passive recipients than active participants involved in the determination of what they are motivated to learn more about from day to day (activity). They are indeed encouraged to ask questions but not to experiment with their knowledge and skills under the guidance of the professionals (doctoring). The parents want to learn as much as possible about the disease and brought all the routines learned at the hospital back home which made the parents efforts in being good parents, managing the child’s disease (individuation) difficult. There is a lack of emphasis on the need for the parent and child to primarily be alert to, and recover sensitivity towards, the child's body signals when it is unwell. The family’s grief was set aside during the intensive education process and it is important for professionals to be aware of family members’ feelings so they can be attentive to those in need of support (sensitivity).

“The Logic of Care” may be useful in order to illuminate and make the educational process more understandable for the involved professionals when a child is diagnosed with T1DM. However, more research is needed if one is to know whether or not it is beneficial to use the theory of Mol [13] in a paediatric context.

**Competing interests**
The authors declare that they have no competing interests.
Authors' contributions
LJ, IH and AL were responsible for the conception and design of the study and the draughting of
the manuscript. LJ and AL performed the data collection and the data analysis discussing the
results with IH throughout the process. IH obtained funding and LJ and IH provided
administrative support. All the authors read and approved the final manuscript.

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References


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<td>Focus on education/training. How was it?</td>
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<td>Person / people you remember from the time in the hospital?</td>
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<td>- for any reason</td>
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<td>The understanding of the implications of the diabetes</td>
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<td>- how did you know about the disease?</td>
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<td>and give insulin injections</td>
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<td>- preparedness to care for your child with diabetes during and after leave and</td>
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<td>discharge</td>
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<td>- on leave (how was it? / what happened after the leave from the hospital?)</td>
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<td>- own ability to influence the care of the child, teaching content and design</td>
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<td>Something that could have been done differently?</td>
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<td>- most important / most useful of what happened during the hospital stay</td>
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