

Research Article

Experiences from Parents to Children with Diabetes Type 1

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OPEN ACCESS**Abstract**

Introduction: When a child is diagnosed with a long-term illness such as diabetes type 1 (DT1) parents often find it stressful to give optimum support to the child and to manage the situation especially when the child is in school. Parents experience that the stress to manage life with Diabetes Type 1, means to constant monitor blood glucose, to assist with insulin injections, food intake and physical activity, in order to optimum disease management.

Aim: To explore how parents' of children with Diabetes Type 1 experienced their role as a parent.

Material and method: A qualitative design was used and individual interviews were conducted with a purposive sample of 13 parents (10 mothers and 3 fathers) of children with Diabetes Type 1. The interviews were analyzed using qualitative content analysis.

Results and conclusions: The analysis resulted in one theme A life change revealing new needs with four subthemes; Struggling with fear and searching for explanations, Learning to manage and getting control of a lifelong illness, Collaboration with school as an important support and Managing the illness influenced work and family finances. Parents in this study struggled for their children at all times, to be the child's caregiver and to take care of the child's life in the best possible way. They asked for flexible and continue diabetes education for themselves and for school staff efficient communication and cooperation between parents/families, healthcare and school.

Keywords

- Child
- Diabetes type 1
- Experiences
- Parents
- Interviews
- Qualitative content analysis

ABBREVIATION

DT1: Diabetes type 1

INTRODUCTION

When a child is diagnosed with a long-term illness like diabetes Type 1 (DT1), the life situation changes for the entire family [1]. Parents are responsible for managing the care of the child and doing so parents experience a lot of stress. To manage life with DT1 involves supporting the child at all times, to constant monitor blood glucose, to assist with insulin injections, food intake and physical activity in order to optimum disease management. Earlier research showed that looking after a child with diabetes was a demanding experience for parents, where the illness experience was dominated by the 'constant-ness' of the disease [2]. Cousino and Hazen showed in a study focusing on stress among caregivers of children with chronic illness, that parents of children with long-term illnesses reported greater general parental stress, than parents to healthy children [3]. A Systematic Mixed-Studies Review showed the prevalence of parental psychological distress across all studies ranged from 10% to 74%, with an average of 33.5% of parents reporting distress at diagnosis and 19% of parents reporting distress 1 to 4

years after diagnosis. Furthermore, parental psychological stress had negative effects on the child's diabetes management [4]. This clearly indicates the burden and impact of the lives of parents with children with DT1. In daily life, children spend a lot of time in school, and it is well described how parents can experience challenges interacting with school and healthcare professions to receive support to manage the child's DT1 in school and daily life [5-7]. School entry represents the first physical and emotional separation from parents and requires parents to trust that school personnel will be attentive and competent to ensure their child's optimal health [8]. The schools cannot always meet children's medical needs and needs for adjustments and parents strive to ensure the child's environment in school can handle urgent situations that may arise in connection to the illness [9]. In many countries are school nurses and school health services responsible for the actual care of children with DT1 in schools [10]. In Sweden the school health services and school nurses are located at the local schools and are a part of the school environment, but not responsible for the care of children with chronic conditions [11]. Parents are the key persons in children's management of DT1 and how parents experiences being a caregiver is important to highlight and understand to improve the care for chronically ill children outside the hospital setting.

Thus, the aim of this study was to explore how parents' of children with diabetes type 1 experienced their role as a parent.

MATERIALS AND METHODS

Qualitative design originated from a holistic tradition and seeks to understand people's subjective perceptions and experiences and was used for reaching the aim of the study [12]. In line with this, data were obtained from individual's interviews [13] and analysed with inductive qualitative content analysis. The method means that the analysis remained close to the text and conducted without preconditions based on parents' experiences [14].

Participants and Procedure

A purposive sample of 13 parents (10 mothers and 3 fathers) participated in the study. Inclusion criteria in this study were Swedish-speaking parents to children with DT1 (age 6-18 years), with two years since diagnosis of DT1. The duration of parents experience of child's DT1 ranged from three to ten years (median=5) and the ages of the children with DT1 (six girls and seven boys) ranged from 6-18 years (median =11). Characteristic variation were attempted by selecting parents, who varied in terms of, gender (female n=10, male n=3), family structure (families n=9, separated n=4), prior diabetes experience of family member/friends (n=3), insulin pump (n=11) or pen (n=2), diagnosis of gluten intolerance (n=3), and ethnicity (born in Sweden n=9).

School nurses from four municipalities in Sweden administrated 30 letters with to parents of children with DT1. The letters consisted of information and aim of the study and an invitation to participate with a response envelope. Fifteen parents responded and were included in the study and the first author contacted the parents to arrange a time for interviews. However, two participants chose not to participate due to lack of time. Therefore, 13 parents were interviewed. The purpose was to reach a purposeful sample with an even gender distribution, but it was difficult to recruit men in the study. Furthermore, the purpose was to identify participants with a range of experiences (e.g., parents with diabetes or other family member) relevant to the research purpose.

Data collection

Individual interviews were conducted with the participants. An interview guide (Table 1) was used consisted of three open questions, Please, can you tell me about your experiences when your child got diabetes? Tell me about your experiences when you and your child returned to home and school? How did you experience support? Participants were encouraged to share their experiences through follow-up questions such as: Can you give an example? What happened next? Two of the authors tested the interview guide in a pilot interview, which was not included in this study. The interviews were audio recorded, transcribed verbatim by the first author and lasted between 35-145 minutes (median= 60). An introduction of the aim of the study was given prior to the interview and background information was retained from the participants. The individual interviews were conducted in Swedish in a quite environment of choice (e.g., in the public library, workplace, university), in January to June 2016 by the

Table 1: Interview guide for parents.

Background
When did your child get DT1?
Do you have a son or a daughter?
How old were your ...at the onset of DT1?
Do you have several children?
How is your family structure? (single or separated homes?)
Are you born in Sweden?
Do you have prior experience from diabetes or DT1? (Family, friends)
Does your child use insulin pen or insulin pump?
Does your child have gluten intolerance?
Questions
Please, can you tell me about your experiences when your child got diabetes?
Tell me about your experiences when you and your child returned to home and school?
How did you experience support?
Can you give an example?
What happened next?

first author. Prior to the interview, written and verbal information about the study was given and informed consent was obtained from all participants.

Data analysis

The interview texts were subjected to inductive qualitative content analysis in line with Graneheim and Lundman [14]. The analyses were conducted in a conventional way without any software. The unit of analysis focus how parents' of children with DT1 experienced their role as a parent. The analysis occurred in five steps: (1) all interviews were read through several times by the authors to get a sense of whole the content, (2) text was divided into meaning units (i.e. a word, sentences or a paragraph with the same content) and condensed, (3) condensed meaning units were abstracted: (4) abstracted meaning units were then reviewed in relation to the aim of the study: and finally (5) compared and sorted into themes and subthemes based on similarities and differences in content. Throughout the analysis, there were on-going discussions between the authors to critically reflect on and review interpretations of the findings throughout the analysis. Finally, all authors met and discussed the analysis thoroughly and agreed the findings [14].

Ethics

Prior to the interview, written and verbal information about the study were given and informed consent was obtained from all parents. Confidentiality and anonymous presentation of the findings were assured. The Regional Ethical Review Board, Umeå, Sweden (Dnr 2015/416-31Ö), approved the study.

RESULTS

The analysis were based on individual interviews on how 13 parents' of children with diabetes type 1 experienced their role as a parent. There were ten mothers and three fathers in the study and the duration of being parent to a child with DT1

ranged from three to ten years. Three parents had prior diabetes experience, one had diabetes type 2, and two had friends and relatives with diabetes type 1 and type 2. The ages of the children with DT1 ranged from 6-18 years. The family structure varied, nine parents lived in families and four parents lived as single parents. Furthermore, ethnicity varied and nine parents were born in Sweden and four parents were born in another European country. All parents had experience of the insulin pen but 11 parents reported using an insulin pump and two parents reported using the insulin pen. Three parents had experience of diagnosis of gluten intolerance as well as DT1.

The analysis of the 13 interviews resulted in one theme with four subthemes describing how parents' of children with DT1 experienced their role as a parent and caregiver. The theme is: A life change revealing new needs was constructed from the four subthemes: Struggling with fear and searching for explanations, Learning to manage and getting control of a lifelong illness, Collaboration with school as an important support and Managing the illness influenced work and family finances. The theme and subthemes are presented below with referenced quotations from the interviews.

A life change revealing new needs

The onset of the child's DT1 was experienced as a life change for the all parents and the whole family. Life would never be the same and parents identified new needs of support and collaboration in order to manage the new situation to be a caregiver to a child with a chronic illness. All parents described the onset of the DT1 when how they struggled with fear and searching for explanations, and later at the hospital learnt how to manage and getting control of DT1, also realizing the illness was lifelong. When returning to everyday life all parents described good collaboration with school as important support and how the life change also influenced parents work and family finances.

Struggling with fear and searching for explanations

All parents described the onset of the child's illness very clear even if it was a long time ago. They reported how they struggled with fear and anxiety hoping the child would recover before finally deciding to seek medical advice. When the child got sick parents described how they felt instinctively that something was seriously wrong, their child was not her/his usual self. They all observed the child and noticed increased thirst, urination, tiredness, weight loss and generally feeling 'out of sorts'. Parent's thoughts were occupied with trying to find logical explanations for the child's changed behavior and they asked relatives, friends and school personnel for support and advice what to do. Three parents were terrified their child had got a deadly illness like leukemia or a brain tumor and they goggled for the symptoms but they did not quite match the behavior of the child. When the parents meet the healthcare professionals all parents expressed relief when they got the diagnosis that their child has got DT1. They finally knew what was wrong with their child. All parents described it as a great support to meet competent professionals who listened and handled the situation in a secure and experienced way. The healthcare professionals made the parents feel safe and cared for, parents describe feeling included and not alone with the responsibility being with skilled competent

professionals. All parents described receiving continuous information regarding the planning of the care and being up to date helped and supported the parents to understand, to feel safe and prepare for the next step.

"We were very well cared for at the hospital and received information fast ...they listened to us ...I was the expert on my child". (Mother-Son 7 y)

Learning to manage and getting control of a lifelong illness

All parents wanted to learn all about the illness to get control of this change in daily life. They described how to learn to manage DT1 through observing, talking and asking questions to the healthcare professionals, but also through the basic education given at the hospital by diabetes nurses and the whole diabetes team (i.e. a professional health care group who work with children and youth with diabetes usually physician, nurse, nutritionist, psychologist, social counselor, and physiotherapist). A few parents describe it hard to learn how to inject insulin or to check the blood glucoses of their child and it was a turning point for them to adjust and learn to manage this. The parents described when they acquired more knowledge about DT1 they also realized their child's illness implied a lifelong medication and constant control.

"It really hit me as a mother; my child needed these injections to stay alive". (Mother-Son 11 y)

The parents expressed that when they and their child came home from the hospital, a new way of life began. Suddenly parents were alone with the responsibility and no nurse to ask when they felt unsure. The food was described as an essential part to manage and they had all meet the nutritionist in the hospital and had discussed strategies to make daily life easier. Three parents had experience of diagnosis of gluten intolerance as well as DT1 and they experienced good support from the nutritionist who presented new food options.

One parent described this new way of thinking, as

"You must learn to think like a pancreas". (Father-Daughter 12 y)

All parents found that the diabetes education in the hospital provided them with a good basic knowledge but not sufficient to manage at home. They expressed a need for more advice, help and support at out-of-office hours. All parents reported seeking and finding support through social media such as Facebook which was available 24/7 in comparison to the support available from healthcare.

"Who is online at 2 o'clock in the night? ..another diabetes parent". (Mother- Son 13 y)

All parents reported Facebook to be a good support especially during the first year with DT1. Parents described different Facebook groups where they exchanged experiences of everyday life as a parent and how to handle challenges like conflicts with teenagers, getting a cold, food recipes, birthday parties, sleepovers and news about new insulin pumps. Parenting a child with DT1 was sometimes frustrating as the children, especially

teenagers, sometimes reacted negatively to increased parental control. Some parents described occasions when the children threatened not to take their insulin or refused to eat and the situation demanded a more authoritarian parent.

"It is a powerful weapon to tell your parents that I do not care about my DT1 ... as a parent you get very cornered and you have to act". (Father-Daughter 11 y)

Collaboration with school as an important support

A good collaboration with the school staff was a great support for the parents and they all wanted to collaborate with the school to ensure the right support for their child. This was even more vital for parents of younger children with less ability to be responsible for self-management. Parents experienced that a good communication with the school staff was vital to ensure the safety for the child during the school day. Some parents experienced a great support from the school staff but some parents were not fully satisfied due to lack of trained school staff and substitute in the classroom. Parents felt responsible for their child's diabetes self-management at all times, even when they had left them at school and they supported the child's self-management by using mobile phones to stay in touch with their child and school staff. Some parents reported how the children took photos of their lunch and send to the parents who calculated the insulin dose needed. This use of modern technology was experienced as a great support from all parents. Individualised care plans from the health care were experienced as positive by all parents. The care plans aimed to improve and support diabetes self-management in school, and reduce unnecessary parental involvement during the school day. Some parents felt like a messenger between the diabetes team and the school when the diabetes team told the parents how it should work in school to be optimal for the child, and the parents had to execute this in collaboration with the schools. All parents described they wanted more collaboration with the diabetes team regarding educating the school staff. They describe that they had been absent from work to educate school staff. Educate the school staff was an important way to ensure that the staff's diabetes competence was sufficient to support their child.

"Me and my husband have continuously initiated education and training for school staff every year. We use our holiday to educate school staff." (Mother-Daughter 18 y)

School nurses was described by some parents as a vital link between school and diabetes team as a support in diabetes issues, to update care plans, to support education of school staff, to communicate with both the school staff and the diabetes team.

Managing the illness influenced work and family finances

All parents reported that managing the child's DT1 affected their jobs and some had changed employments to gain more flexibility to support the child during the school day. Family finances were also affected due to work absences. Most parents had applied for economical support in the form of a childcare allowance for children with a chronic condition. To get the allowance parents had to describe their child as dysfunctional and this discouraged some parents.

"I had to describe my child as dysfunctional as possible for what? ...a small sum after tax... not worth the time.. I try to focus on the positive." (Father- Daughter 12y)

At the hospital, some parents had received support from the social counselor to apply for the allowance while others got support from other parents and social media. Overall parents described Sweden as a good place to live with an open supporting society and legislation that increases understanding of DT1, which made it easier to get a well-functioning daily life, despite the diagnosis. They all described a good future for their children but the parents hoped for increased knowledge in the wider society, so more people would know how to handle DT1 and understand the need for support and individual adjustments for their children but also for the family and parents.

DISCUSSION

This study has provided insight about how parents to children with DT1 experienced their role as a parent and caregiver. The results show that it was a life changing experience for parents when the child got ill. Parents reported how the illness affected the whole family life and how they needed to learn how to manage the illness and also how collaboration with the diabetes team, and school, as well as social media was experienced as support.

Regarding the subtheme struggling with fear and searching for explanations our results suggest that parents experienced support when meeting competent health care professionals who listened to the parents, included them in the care of the children and kept the parents up to date in the planning of the care. This supported the parents and made them feel safe, and enabled the parents to prepare for the next step. This result could be interpreted as a way of empowering the parents by involving and including the parents in the care and to give them structure for the care, with similarities on how person centered care is described [15].

Regarding the subtheme Learning to manage and getting control of a lifelong illness our results suggest that parents had to learn and understand the demands of the illness in order to manage and getting control of the situation. The parents described when they acquired more knowledge about DT1 they also realized their child's illness implied a lifelong medication and constant control. For some parents it was a turning point to realize that it was a question of life and death and that the child needed insulin to survive and the parent had to administer the insulin. We argue that our results have similarities with how the concept turning point have been described, as powerful emotional experiences leading to change in a person's life. Furthermore the experience from the parents could be regarded as a turning point as described in earlier research focusing on illness integration and control of self-care among adults with diabetes type 2 [16].

At home parents reported feeling alone with the responsibility and no one to ask when they felt unsure. The diabetes education gave a good basal knowledge but was not sufficient for challenges in everyday life such as parties or getting a cold for the first time. Furthermore, the parents experience the health care as inflexible and hard to reach especially at nights or weekends. Social media such as Facebook was always available for the parents and was experienced as a support especially during the first year.

Earlier research has shown that diabetes education needs to be adequately resourced and tailored to meet the needs of specific populations like the parents in this study [17]. The parents in this study experienced need for a more flexible and continuous diabetes education during the childhood years. Wennick and Hallström [18] found family experiences of living with childhood diabetes, triggered an ongoing learning process for the whole family and this corresponds well with parents reporting needing more knowledge, seeking and finding support and advice, help and support from different sources, the education given by the diabetes team but also through other parents and through social media. These results are similar to previous research focusing on coping and care giving experience of parents of children and adolescents with DT1, where the highest score was obtained for seeking social support to cope with the parental burden [19]. Some parents described occasions when the children threatened not to take their insulin or refused to eat and parents experienced that the situation demanded them to be a more authoritarian parent than they were before. This change of the parental role were experienced as hard for some parents because they were not used to this way of parenting their child and they felt as a bad parent doing so. Earlier research shows that a more authoritarian parenting was associated with a better glycemic control [20]. Nevertheless, this experience of being a bad and tough parent might add to the parental burden and stress.

Regarding the subtheme Collaboration with school as an important support our results suggest that parents experienced collaboration with school very important, and parents put a lot of effort in this collaboration by being available at all times by mobile phone to support and help the child and the school staff. Parents experienced the use of mobile phones as an important tool in the management of DT1 and were a great support and a possibility to be available for the child and the school staff without leaving their own work. The results in this study corresponds well with earlier research that showed parental involvement had an improvement effect in blood glucoses control and self-management for children with DT1 [21], as well as the use of mobile phones led to improvement in glycaemic control and self-management in diabetes care [22].

Establishing trusting relationships between parents, children and schools staff was found to be a key to success regarding collaboration. All parents experienced school staff to be the most important support for their child in school. This results could indicate the need to further develop the collaboration between parents and school and earlier study has showed how meetings with the school, parents and children, to have a dialogue and to find strategies to support the child in school as a successful way of establishing good and strong collaborations [23].

Educating the school staff was experienced with mixed feeling by all the parents because they had just learned themselves how DT1 should be managed to be optimal for the child, then they had to execute this in the schools. Parents described the diabetes team to be the experts, but the team had no possibility to visit schools but offered schools education at the hospital. Unfortunately, it was hard for school staff to participate due to schedules. The parents experienced it vital that the school staff was competent and felt they had no alternative then to try and educate the school

staff themselves. Kime [24] has shown that parents felt that most of the education of school staff, as well as care and support of the child was left to them. For some parents this was experienced as a burden and they felt caught in the middle between healthcare system and school system. Lack of diabetes competence among school staff has been identified as a problem and an area for development in earlier research [25-26]. Furthermore, a study with school personnel's experiences of caring for youth with DT1 showed lack of education and unclear responsibility to create feelings of uncertainty and insecurity for school personnel and a need for mandatory education of school personnel regarding DT1 and self-care [23]. As mentioned earlier research has shown that diabetes education needs to be adequately resourced and tailored to meet the needs of specific populations like parents or school staff [17] and the result could indicate a need to unburden the parents from educating school staff.

Regarding the subtheme Managing the illness influenced work and family finances our results suggests that parents managed the illness by being available at all times to support the child and the school staff and that doing so affected the parents ability to work. Parents reported they had to be absent from work when the child was not well or when the school called and asked the parent to bring the child home. The family finances was affected and some parents had changed employment or worked part time to gain flexibility. In Sweden there is a childcare allowance for children with chronic conditions and most parents had applied for the allowance but with mixed feeling though the parents had to describe their child as dysfunctional and some parents did not think it was worth the effort and chose to focus on the positive. The findings suggests that even though parents had integrated the illness in their lives, the family and parents was affected especially during the first year after their child was diagnosed with DT1. Despite this, they were also future-orientated and reported that a good life was possible with DT1. This is in line with earlier research focusing on understanding parent's experiences of living with DT1 and striving for normal life [27] and the disease impact on parents and children in terms of health-related quality of life at diagnosis and 1 year subsequent to the child's diagnosis with type 1 diabetes [28].

METHODOLOGICAL CONSIDERATIONS

A qualitative design was considered most appropriate to answer the aim of the study hoping the results cast some light on the studied phenomenon. Different steps were taken throughout to enhance trustworthiness. By clearly describing each step of the research process and presenting verbatim quotes contributes to the trustworthiness of the findings [29]. Participants reported rather heterogenic parental experiences, even though their background varied which increases the possibility of a richer variation of the studied phenomenon [14]. The parents were recruited with a purposive sampling from four municipalities in Sweden. However, no differences between the parents' experiences due to the setting were identified. The risk of bias is always considered and the participants in this study may have an interest to make their voices heard both in positive and negative way. Nevertheless, the participants in this study are representative of parents' of children with diabetes type and the interviews provided rich data. Recall bias should also be

considered, and there were parent who experienced the onset of DT1 ten years ago. Even so, the participants reported a very clear remembrance of the onset of DT1 though this meant a dramatic change of life. In qualitative research methodology, there are no rules for how many participants there should be, the selection is generally determined by the need for data to meet the aim. In this study the data collection was judged to be at the stage where further data collection would not provide more knowledge and the saturation point was judged to be reached. The term saturation derives from grounded theory but is used in other qualitative approaches [30]. The results are not possible to generalise to a wider group as in research with a quantitative design but we view our results as transferable in some extent and may apply to parents of children with other chronic conditions in societies similar to Sweden [31]. However according to Graneheim and Lundman it is up to the reader's judgment as whether or not the reported results are transferable to other contexts [14].

CONCLUSION

The results shows that parents as caregivers are important, maybe the most important resource for an optimal care of children with DT1. Parents in this study struggled for their children at all times, to be there and support the child, to take care of the child's life in the best possible way. Parents asked for; flexible diabetes education for themselves and for school staff, efficient communication and cooperation between parents/families, healthcare and school. The parents report being burdened of continuous stress, little sleep, constant worry, need to available, to educate school staff and manage financial stress. To ensure optimum support to parents and to children with DT1 there needs to be an awareness and consideration for parent's experiences as a complex never-ending responsibility. We argue that it could be logical to unburden the parents by developing a more flexible diabetes online education, easy to reach for parents, school staff and health care as a compliment to the traditional diabetes education given at the hospital.

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