Parents' experiences of caring for a child younger than two years of age treated with continuous subcutaneous insulin infusion

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Summary

Diabetes during infancy is uncommon and continuous subcutaneous insulin infusion (CSII) is the recommended treatment with such young children. However, this form of treatment has not been investigated previously from the perspective of the parents.

The aim of this study was to determine parents' experiences of caring for a child less than two years old who had diabetes mellitus and was being treated with CSII therapy.

Three pairs of parents were interviewed twice to elucidate their views on the initial period and on daily living. Data were submitted to qualitative content analysis and resulted in seven categories and one theme, the latter being: 'The diabetes disease was threatening our baby's life, but then the insulin pump came as a rescuing, though challenging, angel'. Parents initially felt life had been turned upside down, but later they felt in control nearly all the time.

It was concluded that parents of infants with diabetes are in great need of support in order to manage the disease and CSII technology. The fear of losing control and the lack of relief lead to social isolation. Educating someone close to the family could be a valuable intervention.

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Key words

diabetes mellitus; parents; infant; child; insulin infusion system; qualitative study

Introduction

The daily care of young children is the responsibility of their parents, and childhood diabetes has been found to place special demands on parental care and family life. Diabetes requires frequent blood glucose testing, appropriate doses of insulin injections and, moreover, a constant need to make plans for meals and activities.[1]

Childhood onset of diabetes type 1 (T1DM) has rapidly increased, mostly among the youngest children.[2] The frequency of neonatal diabetes (NDM) has been shown to be one in 400 000–500 000 live births; NDM occurs during the first month of life, lasts for more than two weeks and requires insulin therapy.[3,4] NDM can be transient or permanent. Children diagnosed before six months of age usually have a genetic cause of diabetes (monogenic diabetes), and some forms can later, after genetic diagnosis, be treated with oral sulphonylurea. From the age of nine months T1DM dominates.[5–7] Infants with diabetes are vulnerable and require special parental needs, with appropriate education and psychosocial support from a diabetes team.[8]

Regardless of the type of diabetes, these small children need insulin administered in a safe manner. Both NDM and T1DM are treated with either multiple daily injections (MDI) of long- and short-acting insulin or continuous subcutaneous insulin infusion (CSII). Since these children require such small quantities of insulin, it is advantageous to provide it with CSII, which allows administration of small amounts of insulin.[9–11] A historical log documents given insulin doses and stores the information, accessible for parents and professionals.[12,13] CSII therapy in young children has been proven to be safe, with good glycaemic control and few hypoglycaemias.[9–11,14–16]

The experience of transitioning from MDI to CSII, and how this affects the quality of life of children with T1DM, has been investigated in parents, teenagers and school children.[14,16–18] Fathers of children who are 2–12 years old and are transitioning from MDI to CSII viewed the latter as a smooth tool compared to the former. The mothers, on the other hand, first considered the MDI treatment to be safer, feeling insecure with CSII techniques. However, when they had learned to master the technique, both parents and the children experienced better quality of life and a more flexible lifestyle.[19]

Altogether, the use of CSII as a treatment for diabetes in children has been investigated with both quantitative and qualitative designs. However, the experience of parents caring for very young children treated with CSII has, to our knowledge, not been investigated previously.

Aim

The aim of this study was to determine parents' experiences of caring for a child younger than two years old with diabetes mellitus being treated with CSII therapy.

Method

Design

In order to elucidate parents' views both on the initial period and on daily living with CSII treatment, a longitudinal qualitative design was applied and data were analysed according to both manifest and latent content.

Participants

At the time of the study (2003), three children younger than two years old – one girl and two boys – on CSII therapy were identified in Sweden (two of the children had NDM and one had T1DM). All three pairs of parents of these children agreed to participate in the study. Parents were: 25–40 years old; Swedish citizens; co-habiting; and had between one and two children (ages 14 months to 15 years), in addition to the diagnosed child. The mothers were on maternity leave at the time of the child's diagnosis. The fathers were on parental leave from work for a short period of time because of the child's diagnosis. Both parents stayed with their child at the hospital.

The children were diagnosed with diabetes at the age of one week, five weeks, and 14 months, respectively. They were placed on CSII therapy at the age of three weeks, five weeks and four days, and 17 months. The children needed hospital care initially between two weeks and two months. Although children can recover from NDM, all three children required insulin during both the initial and second interview rounds.

Data collection

The participants were contacted when visiting the paediatric clinic diabetes reception. Information about the study was given both verbally and in writing, and written informed consent was obtained from each parent. Two of the pairs of parents were interviewed by one author (AE) and one couple by another author (AL). The interviews lasted between 30 and 90 minutes, and were carried out in the families' homes or at the paediatric clinic, according to the parents' wishes. The parents were interviewed separately, with the exception of one pair of parents who asked for a joint second interview.

The first interview started with the request to talk about the experience of coming home with a baby on insulin pump treatment. The second interview was carried out six months later and started with the request to describe what it was like to live with a child on insulin pump treatment. The interviews proceeded as conversations, with follow-up questions related to the issues that arose.

The study was approved by the Research Ethics Committee (LU 920-03, KI 03-707).

Data analysis

The audio-taped interviews were transcribed verbatim. In a qualitative analysis of the text according to Graneheim and Lundman,[20] meaning units were identified, condensed, abstracted and labelled with codes. These were then sorted into groups, resulting in categories describing the manifest content. Finally, one theme emerged as an interpretation of the latent content. All co-authors were engaged in the analysis. The findings have been discussed in several seminars with researchers experienced in the method. To increase content validity, quotations from the interviews are used to illustrate the findings. These quotations were translated by a professional translator.

Findings

The analysis resulted in one theme and two content areas: (a) initial period with the insulin pump, with four categories; and (b) daily living with the insulin pump, with three categories (Table 1). Throughout the interviews the following theme became apparent:

'The diabetes disease was threatening our baby's life, but then the insulin pump came as a rescuing, though challenging, angel.'

Initial period with the insulin pump

The initial period was coloured by the onset of the diabetes disease '**having your whole life turned upside down**'. The entire situation was turbulent and almost unreal, as if it wasn't really happening to them – like a bad dream.

'I didn't get it. I was so shocked I just left. Because you don't know what it means; because you didn't. Yes, then we felt horribly alone.'

Difficulties planning ahead forced parents to live in the moment, just trying to get by. Other things became secondary when struggling to manage. Feelings of grief, anger and powerlessness came up. *'It felt so unfair.'*

The whole situation was overwhelming; their baby struggling with diabetes and themselves **facing fears and obstacles**. Fears of high and low plasma glucose levels were prominent: *'that the level would be too low or too high, most of all, too low…'*. There were, too, doubts about whether there was enough competence to handle the CSII when in the neonatal care unit.

Theme:	'The diabetes disease was threatening our baby's life, but the insulin pump came as a rescuing, though challenging, angel'	
Content areas	**Round 1 interviews: Initial period with the insulin pump**	**Round 2 interviews: Daily living with the insulin pump**
Categories	Having your whole life turned upside down	Being in control nearly all the time
	Facing fears and obstacles	Being challenged
	Being vulnerable yet confident	Life goes on
	Regaining control	

Table 1. Theme and categories described in the findings

'Yes: at the ward, when we were in the hospital, it would have been nice to know that there was someone who knew the pump. It certainly would have been… So, even if it was like that, you really didn't get the feeling that the staff knew what was going on with the pump.'

The insulin pump was scary to some of the parents, evoking feelings of being in the hands of the technique. It seemed easy to, by mistake, give too large doses, and scary if the machine were to go out of control. *'It felt… even though you could turn it off… it felt so scary that it was a machine, an apparatus.'* The treatment also evoked sorrow: the machine contrasting with the image of a cute little baby.

'To us, it's like a small beeper or something. On him, it was like a huge thing. Rather like a ghetto blaster. You don't want … you don't want your tiny baby to look like that.'

However, parents had no other options than to accept and learn to handle the CSII from the very start: *'with the pens you can't administer such small doses'*. Even so, the worst part of the experience was the feeling of hurting their own child. Holding the baby down to insert the infusion needle and frequent blood glucose controls evoked angst, sadness and frustration.

'When you're to put a needle in your tiny baby, you don't want to make mistakes. You want it to work right away. You don't want to do it twice.'

To have a child with such a demanding illness and treatment was an obstacle, hindering family life in more than one way. Parents interviewed were pre-occupied with the affected child and siblings felt put aside, feeling jealous. *'I remember she* [big sister] *got jealous in the beginning, when we were to check his blood sugar.'*

The interviews gave a picture of a state were the parents were tossed between hope and despair, being **vulnerable yet confident**. The transition from hospital meant feeling alone, while at the same time trying to find confidence in pulling through, managing the situation. *'We felt a great responsibility and so on. It went well, because there were two of us and we could ask each other.'*

Being vulnerable and dependent was a prominent feature: parents relied on the diabetes nurse to help them solve problems with treatment and care needs. *'The very first times she* [diabetes nurse] *put the needles in. It was twice a week. We took the opportunity to bathe our baby.'* Because the child had this special need, family and friends could not offer any help with daily care and the parents reported feeling isolated. *'Of course, we felt alone. Very alone… There wasn't anyone else.'* However, the CSII treatment gave hope, minimising problems such as repeating injections – *'With this pump you wouldn't have to stick him so much'* – and made it easier to handle the situation.

'The expectation before and after we received the pump … was to get better control of the blood sugar level, and I do think it has provided that. It has become much better.'

It took time but it was a relief to **regain control** and recapture parenthood, so parents could, by themselves, care for the child and not be so uncertain any more. *'You knew her, the pump, and the diabetes.'* However, it also took courage to manage the diabetes treatment of such a young and vulnerable child.

'But at the same time, you have to dare. It doesn't work to go around and fuss about it. It wouldn't be good, then; but you have to sort of dare to try until you find the right way.'

Training provided at the hospital was appreciated as a good preparation in helping the parents to gain control. *'It was really good training that we got on the pump.'* The education given was experienced as meticulous and it felt good to have a spare pump to bring home. At the end of the first period, the family had reconsidered life circumstances and had adapted a new schedule for daily life. Although challenging, having diabetes in the family also led to positive consequences. *'We have got used to eating at fixed hours, and that's not wrong.'*

Daily living with the insulin pump

The second round of interviews revealed that the insecurity that characterised the first interviews had passed. The parents now considered themselves to be experts on their child's diabetes and felt

in control nearly all the time. *'Then, as time went by, you became less uncertain, and then you didn't think so much about it.'* However, a constant pressure to be on top of things, and a fear of losing control came up. Parents tried to think ahead to be able to handle any situation coming up: for example, having backup in the form of an extra insulin pump and insulin pens. The routines were both a strain and a source of security in daily family life. *'It is true that we live in a world of routines.'* However, transferring back to insulin pens was not viewed as an option; the insulin pump was considered safer and more controllable. *'God! The pens they're like trying to fix a watch with an axe.'*

The parents still felt insecure about leaving the responsibility to someone else. *'It has become so that we simply don't want to leave her with someone else.'* To move on to day care was a challenge – worrying ahead and planning to be always available. *'Then, also when he starts day care in the autumn, it will feel a bit, a bit, insecure – at least in the beginning.'*

It was **challenging**, with a great responsibility – that is, being responsible for illness treatment. *'You take care of it yourself. It's freedom with responsibility. That demands courage.'* It was especially hard when the child was ill and, still, several months after the diagnosis, new things about the diabetes were discovered.

> *'He's growing constantly. You can never believe with insulin pens or pumps that now it's good; no: it has to be adjusted constantly. The whole time something's happening in the other end.'*

In addition, daily care and solving practical issues with the insulin and the insulin pump were challenging. The disadvantage with the pump was that it is always there and in the way when caring for the child. *'When you're changing diapers and everything, the pump is in the way.'*

Life was going on and the families were about to enter a new, more peaceful rhythm of life.

> *'The difference, generally speaking, between then, when he had just got sick, and now, is, I think, that we have learned to live with the whole thing.'*

Coping, adjusting, and finally accepting this new way of life meant having one's life arranged around the affected child's needs. It meant giving up a social life, accepting that it was not possible to improvise and, for example, just go swimming on a hot summer day. Sacrifices could make the parents sad, but on the whole it was worth the effort, to keep life on track. *'The majority of the time you accept it. You accept it for what it is. You don't have any choice, and then that's what it is.'* And also having hope: *'I do believe there is hope, after all. There is so much research going on in this.'*

It had taken a lot of time and effort to make things work and, now, several months after the diagnosis, the families seemed to be coming out of this crisis strong and confident. *'Now it feels like we're going to make it.'* Over time, the diabetes had become a natural part of their life and that of the children; both the affected child the siblings saw the insulin pump as natural. *'He seems to be happily unaware of his insulin pump.'* Resources, such as medical support from the diabetes team, and grandparents helping out with babysitting siblings and other practical concerns, were of priceless value to the parents. *'She* [grandmother] *helped a lot.'*

The parents still saw the insulin pump as a necessary tool; however, they accepted it as a part of life and valued it as important for their child's well-being. *'It's a tool. It's not a cure. That's a big difference.'*

Discussion

Although parents' experiences with CSII treatment were the focus of this study, a competing content came to the fore in the narratives. The diabetes disease, as a threat to the child concerned, emerged as the most prominent aspect of the experience. CSII, including the pump, was seen as a rescuing but challenging tool.

All of the interviews from the first round were permeated by a feeling of powerlessness and turbulence in relation to the diagnosis, with parents wishing for more support and relief. That the onset of the child's diabetes is a crisis is known from earlier studies with older children.[21–24] Hall described parents having an 'out of body experience', hovering between hope and despair.[21] Wennick and Hallström promoted individual care plans to meet the special needs and requests of families with children treated for T1DM.[22] Lowes *et al.* described the diagnosis of diabetes as a psychosocial transition.[23] All parents in the present study talked about being dependent on nurses' support to be able to care for their child; the diabetes nurses were specially mentioned. These findings are supported by Armentrout, who found nurses' emotional support and guidance important to families having a child with NDM.[25] This places special demands on nurses, when organising appropriate care.

Since diabetes onset in childhood requires hospital care, and children with NDM are cared for at neonatal units, a close collaboration between the diabetes nurse and the neonatal nurse is needed. Parents in this study reported that they perceived the nurses at the neonatal unit as inexperienced in handling the CSII apparatus. However, NDM is rare, and, consequently, CSII is not a common treatment in neonatal care. Problems related to competence when a disease or effective treatment is unusual link to the issue of human rights. The United

Nations Convention on the Rights of the Child[26] recognises children's right, and all children – even when affected by a rare disease – have the right to health, safety, and special competence in health care professionals responsible for their care. Parents need to feel secure that their children's medical needs are taken care of. They want to know that competent professionals will inform, guide and support them. The health care system needs to live up to these expectations, having routines for the more uncommon diseases. Collaboration between different areas of specialisation in paediatric nursing care is important in these circumstances and, since NDM occurs as seldom as two to five times a year in Sweden, a national competence team could be required.

Hall found that being given a realistic picture of the child's condition, and allowed to be involved in the medical decisions regarding the child, contribute to the family's well-being.[21] In the second round of interviews in the current study, the parents described feeling like experts on their child's care. This progression from dependent to expert is in concordance with the findings in a review about families' experiences of being technically dependent on a ventilator.[27] The health care system has to support parents who care for severely ill children.

In agreement with the current study, earlier research has shown that the child's diabetes influences the whole family situation.[1] The lack of relief came up in both rounds of interviews and is supported by previous research.[24,28,29] Support groups for parents of children with diabetes, where parents can discuss problems and strategies with others with similar experiences, could be an option. Such groups were found to lessen feelings of isolation, particularly among mothers. Websites where parents could find other parents in similar situations with whom to chat could also be a possible source of support.[24] Low social support can be associated with parental burnout, and nurses in clinical practice need to be aware of such symptoms.[28] Engaging mothers with experience of having children with diabetes as mentors for mothers with newly-diagnosed children of the same age was found to be feasible and potentially effective.[29] Since diabetes is a rare phenomenon in such young children, it is not easy to create peer support for parents, but a website perhaps could enable parents to get in touch with each other.

KEY POINTS

- CSII is valuable for parents when caring for a child younger than two years old with diabetes
- Parents of infants with diabetes are in great need of support
- Educating someone close to the family could ease the strain and prevent social isolation

The demanding situation could be expected to cause a great strain on the cohesion between the parents, but the three pairs of parents in this study expressed the opposite. A strong affinity between the parents and the children emerged when fighting a common enemy: the diabetes. The parents appreciated the ability to cooperate and share responsibility when coming home from the hospital. The importance of parental collaboration was highlighted both by Smaldone and Ritholz[24] and by Lindström *et al.*[28] This must be promoted in clinical practice, involving both parents in the education after the diagnosis and at the introduction of CSII. Problems with babysitting were brought up in both interview rounds, supported in previous research.[24,28,29] The authors of this study suggest also the inclusion of a few close relatives or close friends in the education. This could relieve some of the strain on the parents.

Both advantages and disadvantages with the use of CSII came up in the interviews. When six months had past, all parents felt confident with the technique of CSII. However, some of the parents reported that they had needed a little more time before feeling safe. Also, mothers of children aged 2–12 years old felt insecure about the CSII technique in the beginning, and considered MDI treatment to be a safer way in which to administer insulin. However, once these mothers had mastered the technique, they preferred CSII.[19] Similarly, life without CSII was not seen as an option by the participants in the current study. CSII required fewer 'pricks' and enabled fine-tuning of the diabetes regimen. However, having the CSII was seen as more awkward than MDI, related to the fact of being present all along. The CSII then became a kind of manifestation of the diabetes and, as expressed in the overall theme, it was the diabetes disease that was experienced as the true threat to the child.

The sample size can be considered as limiting the significance of the findings in this study. However, the sample represented different aspects of the experience: the first period and after six months; newborns and one-year-old child; no previous experience of diabetes treatment; and previous experience of MDI injections with an older child. Another factor, of importance to the findings is the fact that the interviews were conducted 10 years ago. However, the results presented in this study have recently been confirmed in clinical contacts with the parents of the actual patient group. CSII is a recommended and, perhaps the most relevant, treatment for very young children who are insulin dependent.[4,9,10,25] Hence, the parental perspective when such young children have CSII treatment needs to be highlighted, and further research is required.

Conclusion

Parents of infants with diabetes are in great need of support to manage the disease and the use of CSII. The fear of losing control and the lack of relief lead to social isolation. Educating someone close to the family could be a valuable intervention. The experience of taking care of children with NDM is still a fairly unexplored area; this needs to be put in the spotlight due to the increase of diabetes in very young age groups and the special needs of these children and their families.

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Declaration of interests

There are no conflicts of interest declared.

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