

Mothers' experiences of caring for an adolescent with recently diagnosed type 1 diabetes

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Summary

Background: Increasingly more children and adolescents are being diagnosed with diabetes, which is a common disease in this age group. The diagnosis normally comes as a shock to the parents, and they have to learn a lot about medical treatment and lifestyle changes in a short period of time. Mothers often experience more stress than fathers. Adolescence is a transformative period in which independence is pivotal and the role of parents is challenged. Puberty leads to unstable blood sugar levels and an increased need for insulin at times. Being able to cope with the situation is crucial to the parents' own well-being and to their child's quality of life.

Objective: To describe mothers' experiences of caring for an adolescent with recently diagnosed type 1 diabetes in order to shed light on parents' needs for support from healthcare personnel.

Method: The study has a qualitative design and includes eight individual interviews with mothers of teenage children with recently diagnosed type 1 diabetes.

Results: The mothers talked about crisis reactions and the pressure of expectation. They were shocked by their child's illness and worried about everything they had to learn about diabetes treatment as well as their child's own management of the disease. The mothers were not given the opportunity to talk with the healthcare personnel without their child being present. They said that they coped with the situation by processing what was happening, learning through experience and acknowledging the need to spend time on these things. They reported communication challenges, both within the family and with healthcare personnel, and understood that adolescence is a vulnerable time in which their parental role can be tested. By finding the right balance between managing the treatment and gradually transferring the entire responsibility to their child, the mothers tried to maintain their child's quality of life.

Conclusion: The mothers developed coping skills by processing their emotional reactions and implementing problem-oriented measures to solve the challenges of the disease and the treatment. The child's quality of life is a common goal for parents and healthcare personnel. Parents also have to help their child develop self-insight and independence in terms of managing the treatment. Parents need support from healthcare personnel and guidance on how they can best follow up their child.

When an adolescent is diagnosed with type 1 diabetes, it affects the life situation of the entire family. The parental role is challenged, particularly since they are in the process of gradually detaching themselves from their parents and taking responsibility for their own health (1, 2).

Adolescents need knowledge, experience and skills to succeed, and parents, friends and healthcare personnel provide valuable support (2). It is stressful for both parent and child when the disease first emerges, often in acute and dramatic circumstances.

The diagnosis comes as a shock to the parents

Type 1 diabetes is the second most common chronic disease in children (0–17 years) in Norway. It can lead to serious complications, a reduced quality of life and premature death (1). In 2018, 431 children in Norway were diagnosed with diabetes, and 28 per cent of these developed life-threatening acidosis (1) despite the fact that the disease develops over time and is characterised by various signs.

A literature review showed that parents will normally experience shock, anxiety, stress and a feeling of lack of control in the beginning (3). In order to be better placed to absorb the complicated information they are given on the treatment of diabetes, parents need to feel reassured (4).

When a child develops diabetes, mothers experience more emotional strain and a lower quality of life than fathers (5, 6). Mothers' post-traumatic stress symptoms can persist for up to five years, and their ability to cope with stress can affect their child's behaviour and ability to keep the diabetes under control (7).

Communication is essential

Hormonal changes in teenage children increase the need for insulin and make it difficult for them to keep the diabetes under control. Treatment is nevertheless essential for facilitating growth and puberty and for reducing the risk of sequelae (1).

Parents care about their children's quality of life, which is defined here as the sense of well-being and having a basic sense of joy (8). Adolescents report that friends, parents and self-esteem are the most important factors for a good quality of life (9).

It is essential for parents and teenage children to communicate (9). However, another study of adolescents with diabetes and their parents shows that they often avoid sharing their thoughts and feelings in order to protect each other (10).

This can lead to misunderstandings, frustration and feelings of loneliness, and can result in worries and problems remaining unresolved (10). A third study found that it is easier for adolescents to open up to their parents if they are asked directly how they are feeling (11).

Healthcare personnel can teach parents how to cope

When the illness is first diagnosed, parents feel a sense of shock at a point when they need to process new information and develop new skills, whilst also having to act as reliable caregivers (12). Research shows that healthcare personnel can help teach parents effective coping skills that make the role of carer less stressful and more rewarding (13).

A national service user survey at outpatient clinics in 2017 found that less than a third of the parents felt they were given enough time to talk to healthcare personnel without their child being present (14).

Lazarus and Folkmann (15) describe coping strategies as cognitive (through developing a different understanding of the situation), emotional (through reducing the feeling of despair and stress) and problem-oriented (through actions to reduce the problems).

Objective of the study

The objective of the study is to describe mothers' experiences of caring for teenage children with recently diagnosed type 1 diabetes. The aim was to shed light on the needs of parents when their child is diagnosed with this chronic disease.

Method

The study has a qualitative design, which is based on semi-structured individual interviews. We wanted to obtain a broad understanding of parent' experiences of caring for teenage children with recently diagnosed type 1 diabetes and their experiences with healthcare personnel.

Sample

We recruited parents from the specialist health service. Both the parents and their teenage children were invited to participate in the study, but this article only addresses the parents' experiences.

The inclusion criteria were parents of teenage children (13–17 years) who had been diagnosed with type 1 diabetes in the past two years. The participants had to be fluent in Norwegian. We invited the parents of 28 teenage children to participate. The eight who agreed to take part were all mothers.

Data collection

The interview guide consisted of open-ended questions related to topics such as illness, follow-up by healthcare professionals, coping, the parental role and the child's self-care and quality of life. We wanted to obtain knowledge about the parents' experiences through their own descriptions of everyday life.

We collected data between 2010 and 2013. Two of us interviewed the mothers at locations of their choosing, mainly at home with their family. The interviews lasted 40–90 minutes, and only the informant and the researcher were present. We made audio recordings of the interviews, which were then transcribed verbatim.

Research ethics

The Regional Committee for Medical and Health Research Ethics (REC) approved the study (reference number 2010/1134). The informants received an information letter, and we obtained written informed consent from the parents and their children.

We deidentified the interviews in the transcription, and quotes are not linked to the individual informant. The children consented to their parents being interviewed. We would like to emphasise that seven of the eight children were under the age of 15 at the time of diagnosis.

Analysis

We conducted an abductive analysis, which involves both an inductive and a deductive approach (16, 17). First, we read the interview text in its entirety, then we condensed it into meaning units and formulated descriptions of the main manifest content of the text (18).

We then synthesised these condensed meaning units into sub-themes and interpreted them by asking analytical questions about the content based on our experiences and theories of coping and quality of life (17, pp. 224–6).

This process of interpretation helped to elicit the underlying meaning, i.e. the latent content. From the sub-themes and the underlying meaning, we formed the main themes (17, 18) (Table 1).

Table 1. Example of the analysis process

Meaning unit	Manifest content	Sub-theme	Latent content	Main theme
'All the training sessions were shortened, but there were more every day. [...] so I was like "I can't take in any more information now. I've kind of reached saturation point."'	The mother was unable to absorb any more information	Overwhelmed by information at the time of diagnosis	Given a lot of important information, but has a reduced capacity to absorb new information	Crisis reactions and pressure of expectation
'And so I managed to tell them, that "now ... now it's enough. There's no point. It's just ... going in one ear and out the other. I know it's important for me to understand these things, but I can't take in any more"'	The mother managed to speak up	Ability to express the need to control the volume of information	Takes responsibility for receiving the right amount of information	Coping with the situation

Results

The data are based on eight interviews with mothers of teenage children with recently diagnosed type 1 diabetes. Seven were ethnic Norwegian, and one had another ethnic origin. All had more than one child. Four mothers were married and four were divorced. The children consisted of four boys and four girls between the ages of 13 and 17. All had been diagnosed 8–22 months before the interview.

We identified three main themes in our analysis of the findings:

1. Crisis reactions and pressure of expectation
2. Coping with the situation
3. Safeguarding the children's quality of life

Crisis reactions and pressure of expectation

The experience of shock and grief was a common theme in the mothers' accounts of being given the diagnosis. Several had a bad conscience about the time that had elapsed between the first symptoms and the diagnosis, such as this mother:

'So it was a shock... yes, it really was. And then, of course, as a mother, you get like "God, why didn't I notice anything" and... and then it hits you, I did notice that [name] was not in great shape. You know... He was constantly going to the toilet.'

Despite the fact that the mothers were experiencing a crisis, they felt that healthcare personnel expected them to cope with the diabetes treatment straight away. One mother described it as follows:

‘We went straight to the exam... Without having opened a book. So, that... that feeling I think is perhaps best described as: A bit like... running a marathon without having trained, standing on an opera stage; with a full audience, everyone expecting you to be able to do this. And you can’t sing a note.’

The mothers’ and fathers’ roles varied

Several of the mothers said that they needed to talk with healthcare personnel without their child being present, but only one of the mothers had been given the opportunity to do so. Many also emphasised that they needed the information they received at the point of diagnosis to be repeated in order to understand the treatment and feel more reassured.



«In several cases, it was revealed that the mothers did not always have faith in the fathers and struggled with allowing them to play a role.»

The roles of the mothers and fathers in following up their child manage the treatment varied, and by their own account, the mothers assumed the main responsibility. Some mothers felt that they lost control of the management of the disease when their child was living between two homes.

They worried that the fathers’ lack of insight into the disease would have a negative effect on the management of the disease. This was also the case in some families where the parents lived together. In several cases, it was revealed that the mothers did not always have faith in the fathers and struggled with allowing them to play a role.

Coping with the situation

The mothers described how everything felt chaotic in the beginning, but that they coped better after a while. The strategies they adopted could be conscious or unconscious. Some strategies entailed trying to process their emotions and those of others, and some related to their child’s learning process.

Some mothers described how they were in denial at first. They had hoped that it could be a misdiagnosis: ‘You feel it ... the fanciful thought comes almost immediately: “It’s a mistake, a misunderstanding. It was the wrong blood test.”’ Others said that if they compared it to more serious illnesses, they felt relieved that ‘it was just diabetes’.

The adolescents should take more responsibility

The mothers wanted to take a positive approach to the new life situation in order to help their child accept that they have a chronic illness. One mother provided comfort as follows: 'You're lucky, you have an illness that can be treated and you can still have a long life. You can spend time with your friends and take part in activities.'

Another mother described how she tried to let go and give her teenage child the opportunity to take responsibility for managing the treatment:

'[...] but I'm trying to teach myself how to just let them make their own choices, and not... not worry. But... but obviously, I worry subconsciously a lot of the time.'

In order to be able to cope with the situation, it was important for the mothers to find the right balance between supporting their child and transferring responsibility. All the mothers pointed out that their child would have to be able to manage the disease on their own in the long run.

The mothers had varying degrees of control

The adolescents had to take responsibility for their blood sugar control and insulin regulation, but the mothers' strategies for supporting the development of independence varied. One mother felt that she had full control over the treatment, while another delegated all responsibility to her child.

Most mothers were somewhere between these extremes; they both exercised control and transferred responsibility. The parents wanted to trust their children, but found that they could be careless in their management of the disease.

One mother said: 'So we have to be aware, we definitely do. Preferably without fussing too much though.' The mothers realised that their monitoring of the situation could be interpreted as having a lack of trust in their child and could be a source of irritation:

'So I phone... she's still sleeping – I phone again. And I phone in the evening as well to find out where she is. She thinks I'm stalking her. But... but I tell her "you'll appreciate this when you're older".'

Maintaining the adolescent's quality of life

According to the mothers, their teenage child's quality of life was satisfactory, but was also a delicate balancing act, especially when other challenges arose. Some mothers felt that their child was extra vulnerable, and wondered what could be attributed to the disease and how much was down to puberty.



«Friendships, school and leisure activities were all crucial to their quality of life.»

The mothers believed that their child's quality of life was dependent on the disease being a less central part of everyday life. Friendships, school and leisure activities were all crucial to their quality of life. One mother said:

'Of course it's affected [everyday life], but his quality of life... I think he's kind of managed to maintain the same quality of life more or less. He does the same things, he has the same friends, so. He exercises, he eats the same things pretty much.'

The mothers described their teenage children's quality of life as 'getting back to where it was', but that it was also 'a bit more governed by the things they had to do'. The mothers highlighted how the diabetes treatment made their children feel different from their peers and sometimes resulted in poor self-esteem.

The risk of hypoglycaemia was frightening

Several mothers said that the biggest challenge was achieving satisfactory long-term blood glucose levels, and that the risk of hypoglycaemia was frightening to their child. One mother described it as follows:

'She says herself that she notices it if her blood sugar levels are really high or really low. But a few times it happened really quickly, and she was absolutely terrified.'

Findings show that healthcare personnel can help maintain the adolescent's self-esteem and quality of life through communication and by paying attention to the adolescent's everyday life and resources, in addition to the disease itself. One mother made the following observation:

‘He [the doctor] asked about school, how far he had come, about sports and football and how he was managing it all... if he’d found a good solution for dealing with the training sessions – with food or insulin and that sort of thing.’

Discussion

The mothers adopted different strategies to cope with stressful experiences and to support their children. Some used emotional strategies, such as the magical idea that the diagnosis was wrong. Others used strategies that were based on cognitive coping processes and finding the positive in the situation (15).

The mothers’ descriptions reflect their need to process reactions and gain practical experience with the disease over time. Research shows that parents must adapt to ‘the inevitable’ and understand that the learning process is ongoing and constantly requires changes to be made (19).

Additionally, post-traumatic stress reactions can last between one and five years (7). One study shows that in order for parents to be able to absorb the information they receive from healthcare personnel, the information should be parent-centred and designed to accommodate reactions of shock and grief (6).



«Healthcare personnel should focus on why certain things should be done, rather than just telling the parents what should be done.»

Adopting problem-oriented strategies enables parents to implement appropriate measures. Meanwhile, healthcare personnel must also recognise that it takes time to integrate knowledge, attitudes and skills, and they must communicate this (14).

Research also shows that when parents receive training, healthcare personnel should focus on why certain things should be done, rather than just telling them what should be done (6).

Mothers had the main responsibility

Several of the mothers found it stressful when they and the fathers had different views on the management of the disease. The mothers had the main responsibility, which is confirmed by a Norwegian study in which 80 per cent of those who accompanied their child to a diabetes check-up were mothers (20).

Earlier research shows that mothers feel more stressed about blood sugar levels than fathers (21). A literature review found that poor family dynamics and stress due to the disease have a negative impact on adolescents' glycaemic control (22).

Meanwhile, another study shows that although fathers do not usually have the main responsibility for the daily treatment, their contribution through understanding, knowledge, adaptation and behaviour can nevertheless play a role in coping with the disease (23). The fathers' involvement has the potential to reduce the mothers' stress, strain and anxiety (23).

Such support can therefore protect mothers from over-involvement and create a shared responsibility between the parents. It can also make it easier for their child to take responsibility for their own health.

Follow-up of the adolescents was necessary

Healthcare personnel can probably help fathers to get more involved by inviting them to discussions about their important role. According to a national service user survey, parents want time alone with healthcare personnel, especially in relation to discussing the psychological challenges of diabetes and how to approach these (14, 24).



«A large degree of parental follow-up combined with less psychological control will facilitate children's management of the treatment.»

Although mothers receive criticism from their children when they, for example, remind them to check their blood sugar, research supports the importance of such parental follow-up. A large degree of parental follow-up combined with less psychological control will facilitate children's management of the treatment (25).

This is supported by our findings, which show that the mothers wanted to participate in the management of the disease without taking over responsibility from their child. Other research confirms that in order to maintain fruitful communication with their child, parents need support to respond appropriately and in a non-invasive manner (26).

Normality in daily life is key

This study shows that the communication between mother and child is perceived as a challenge, and research shows that it may be beneficial for healthcare personnel to explore communication patterns in the family in order to better support the learning process, treatment management and transfer of responsibility (11, 26).

In earlier research, adolescents have said that friends, parents and self-esteem are fundamental to their perceived quality of life (9). Mothers want their children to maintain a good quality of life and feel good again.

A study of the relationship between adolescents, parents and healthcare personnel identified three key elements that were needed for adolescents to learn life skills: developing new relatedness with parents and healthcare personnel, becoming decision-makers in their own lives with diabetes, and personal growth (27). These elements are confirmed by our findings.

The mothers emphasised the importance of protecting their child's integrity, and of informing their peers and other significant adults about the disease. Both our findings and the results from another study (11) show that security and normalcy in everyday life are crucial to being open about and accepting the disease.

Strengths and limitations of the study

We followed Graneheim and Lundman's (16) principles of analysis and ensured credibility by having two researchers carry out the analyses independently of each other. The coding was consistent between the researchers, and we discussed some different understandings of the data material, which improved the categorisation and understanding of the findings.

We conducted co-author checks and peer debriefing to assess the credibility of our interpretations. We undertook several joint reviews of the main findings during the analysis process and discussed the interpretation of the data.

The study consisted of eight informants. The results cannot be generalised, but several of the findings reflect similar experiences. The data were collected in the period 2010–2013. We do not consider the timing to be particularly relevant because we believe the parents' experiences are just as relevant today in that they relate to experiences in the initial phase of a chronic disease, and little has changed in the approach to this in recent years.

We consider the study to be a reliable method for interviewing parents about their experiences. The data material collected shows a high degree of internal validity in that it helps to answer our problem, achieves the goal of the study and elucidates the phenomena we wanted to shed light on (28).

The informants have a lot in common

It is a strength of the study that the parents are informants and are in similar situations in relation to the child's age (adolescents), the child's illness (type 1 diabetes) and time since diagnosis (within the first two years). The findings may, therefore, also be transferable and recognisable to other parents in the same situation.

The authors are two public health nurses and a paediatric nurse with experience in working with parents and adolescents. We regard this as a strength, but it can also represent a challenge because our experiences could potentially influence the analysis.

Our reliability may therefore have been affected to some extent by our preunderstanding, even though we consider both the findings and the analyses to have a high degree of validity and reliability as a result of the joint reviews of interpretations carried out during the analysis process (28).

Conclusion

The mothers experienced varying crisis reactions after their child was diagnosed with type 1 diabetes. They also felt that healthcare personnel had expectations of how they should handle the new life situation.

How well they succeeded in this affected their sense of coping and their perception of whether they were providing good care. Their experiences show that coping skills are developed by adopting various strategies based on processing emotional reactions and focusing on problem-oriented measures.

Finding a balance between the mothers' need for control and the delegation of responsibility for the treatment to their child improved the coping skills and quality of life of both parties.

The adolescent's quality of life is a goal of parents as well as healthcare personnel. Taking responsibility for their own health can improve an adolescent's quality of life. It is important that healthcare personnel include both parents in the management of the disease.

Parents may need guidance and support on how best to behave in order to successfully manage the disease. Findings in our study and other studies (14, 24) show that parents are rarely given the opportunity to discuss matters with healthcare personnel without their children being present.

An exchange of experiences between parents, in the form of a peer/mentor initiative or through participation in group meetings, is another research-based measure that can be offered. The school nurse can offer health-promoting conversations with the adolescents and the parents separately in collaboration with the specialist health service, but more research is needed in this field.

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