Everyday life of a family with diabetes as described by adults with type 1 diabetes

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Summary

Diabetes mellitus is a common chronic disease. According to previous research, family has an important role in the management of diabetes among children and adolescents.

The aim of this study was to describe how adult people with type 1 diabetes experience everyday life in their families.

The Straussian grounded theory method was used to analyse data collected by interviewing 19 people with type 1 diabetes.

On the basis of the data, eight concepts describing different views on everyday living with diabetes were generated: managing hypoglycaemia; balancing self-management needs; performing daily routines in the family; living with changing feelings; diabetes being invisibly present; protecting the family's well-being; the family members variously contributing to the self-management; and learning to live with diabetes in the family.

In conclusion, everyday life in families includes many different issues and family members are involved in the self-management of diabetes in many ways. In the interests of developing family-centred education and care, it is important to understand how adult people with type 1 diabetes experience everyday life within their families.

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Key words

diabetes mellitus; adult person; family; everyday life

Introduction

Diabetes mellitus is one of the most common chronic diseases all over the world. The aim of diabetes management is good metabolic control, the prevention of diabetes-related complications, and good quality of life. The person with diabetes is responsible for his/her self-management. Self-management is affected by several factors, such as feelings, attitudes, self-efficacy,[1–4] knowledge and skills, and the motivation of the person with diabetes.[5] In addition, patient education and social support have an effect on the individual's self-management.[6,7]

Previous studies[8,9] have shown that family has an important role in the self-management of children and adolescents diagnosed with diabetes. The role of family members is especially important with regard to emotional support. In addition, family members can offer practical help for self-management.[9] The significance of the family members has also been emphasised in studies conducted on people with type 2 diabetes.[10–14] Family members encourage and support the self-management of diabetes.[11,15] On the other hand, family members have even more worries connected with diabetes than the person with diabetes, and these can cause him/her stress.[16]

The self-management of diabetes takes place in the family's everyday life, and it is important to know how adult people with type 1 diabetes experience everyday living within the family. The purpose of this study was to explore the experiences of everyday life in families from the point of view of adult people with type 1 diabetes.

Method

Data collection and analysis

The data for this study were collected by interviewing 19 adults with type 1 diabetes. The interviews took place in the participants' homes or in the first author's office. The duration of the interviews varied from 40 minutes to 2 hours. With the participants' permission, the interviews were audio-recorded. All interviews were transcribed verbatim.

This study used grounded theory based on Straussian principles. According to Strauss and Corbin, the whole analysing process consists of the phases of open, axial and selective coding.[17,18] The analysis started with an open coding of the data. First, the verbatim transcribed text (353 pages) was read line by line several times, searching for expressions describing everyday life with diabetes. Then, every word and sentence were analysed, in order to derive substantive codes from the data. Substantive codes were created close to the text. Altogether, 925 substantive codes were created. After that, substantive codes with similar content were classified under preliminary subcategories. Twenty-eight subcategories were discovered during the analytic process.

During the axial coding, the main focus was on grouping the subcategories into main categories by constant comparison, by asking questions about the material, and by writing memos.[17,19] Subcategories with similar properties were listed under a specific main category.

Concepts describing everyday living with diabetes were based on eight main categories, which describe the thoughts of people with diabetes on everyday living with diabetes. This study is part of a larger study, where the main categories of two datasets will be combined by using selective coding. The other dataset consists of the interviews of family members nominated by adults with type 1 diabetes. To develop the care and education of the people with diabetes, it is important to discuss separately the issues of everyday life with diabetes from the family members' point of view. After combining the two datasets, it will be impossible to address the point of view of the people with diabetes clearly.

Ethical considerations

The Ethics Committee of the Pirkanmaa Hospital District has given a favourable statement for the research plan of this study. Approval for this study was also obtained from the University Hospital and from the Diabetes Association. The participating adults with diabetes were provided with written information about the objective of the research and a consent form to be signed. Voluntary participation and protection of anonymity were emphasised. Permission to audio-record the interview was sought.

Results

The study participants were people with type 1 diabetes, aged 28–65 years (mean age 42 years). Of the 19 participants (18 females, one male), 17 were either married or cohabiting. Seven of them had no children, and in the case of five participants' families the children were already adults. The duration of diabetes ranged from 2–58 years, the mean duration of diabetes being 28 years. The participants were diagnosed with type 1 diabetes during childhood or adolescence. Only in one family was the diabetes diagnosed during the marriage. When presenting the results, the term 'people with diabetes' is used to refer to the study participants with type 1 diabetes.

Managing hypoglycaemia as part of the family's everyday life

In the participants' families, the possibility of hypoglycaemia was present almost every day, and episodes of hypoglycaemia were also common. Individuals with diabetes kept chocolate, juice or dextrose with them all the time to prevent the occurrence of hypoglycaemia. Additionally, the other family members kept something with them just in case. Sometimes episodes of hypoglycaemia arose without any previous symptoms, and they surprised the person with diabetes as well as the family members. The people with diabetes said that sometimes their spouses recognised the symptoms of hypoglycaemia before they did themselves, by observing their behaviour. Hypoglycaemia was experienced as an unpleasant condition where the individual with diabetes cannot control his/her actions. The people with diabetes thought that seeing hypoglycaemia is scary for the family members and especially for the children. For this reason, they did not want their family members to notice hypoglycaemia at all. Sometimes the person with diabetes described the symptoms of hypoglycaemia to a family member, but often they took care of the situation unnoticed. The individuals with diabetes mainly took care of hypoglycaemia by themselves, but their family members also gave them something to eat, or they requested them to eat.

'When I'm little bit feisty, my husband asks me if I have hypoglycaemia,' (interview 18A).

'Then they [my family members] *learnt to keep chocolate with them, and every time I'm cranky they give me some,'* (interview 1A).

Avoiding hypoglycaemia was described as being necessary to manage everyday life. The people with diabetes kept their blood glucose levels sufficiently high – meaning higher than their blood glucose target level – just in case. They performed blood glucose measurements several times during the day, injected less insulin than necessary, and ate extra snacks.

Balancing self-management needs

The people with diabetes said that they were responsible for their own self-management. In addition, they were responsible for solving problems and making decisions related to the management of diabetes. They took care of the concrete self-management routines, such as injecting insulin or performing blood glucose measurements. Even so, the self-management of diabetes was visible in many ways in the family's everyday life: there was treatment equipment all over the house, insulin in the fridge, a blood glucose monitor on the table, and chocolate for treating hypoglycaemia in the kitchen cupboard. The family members also saw the various self-management routines, such as blood glucose measurements and insulin injections, during the day. On the other hand, sometimes the person with diabetes tried to perform their self-management unnoticed, especially with regard to children.

'It's some kind of a private thing, and there's no need to explain it to the family. I'm responsible for it,' (interview 5A).

Sometimes there was not enough time for self-management. The insulin injection or blood glucose measurement was forgotten, because there were more urgent matters to attend to, for example: children's needs. The adults with diabetes left their self-management in the background on purpose, and planned to

take better care of it on the following day or week.

In addition to carrying the responsibility, the participants with diabetes discussed the management of diabetes with their spouses or other family members, and together they made decisions connected with the management of diabetes. They conferred on blood glucose values and reasons for unusually low or high values. The people with diabetes appreciated sharing diabetes-related matters with their spouses or other family members.

Performing daily routines in the family

The daily routines in the family's everyday life include many chores; for example, household work and child care. In addition to that, there was a need to work for an income. Because of diabetes, the day must be planned beforehand. For families affected by diabetes, it was impossible to act spontaneously, and there had to be an exact schedule for the day. This schedule was followed by all the family members.

'My daily life… it goes on the children's terms,' (interview 9A).

Sometimes the family's daily routines changed as a result of the management of diabetes. Because of diabetes, there were extra worries and expenses, and making ends meet was often challenging. The person with diabetes must often visit the hospital or outpatient clinic, and it was the other family members' responsibility to take care of the daily routines in the family.

Living with changing feelings

The people with diabetes had to live with different feelings daily. The feelings might vary from satisfaction to dissatisfaction and annoyance, from happiness to sorrow, and from enthusiasm to fatigue. According to the people with diabetes, blood glucose levels affected their mood. When the levels were high, they were nervous, cranky and depressed. This affected the whole family as well.

'Sometimes I'm so angry that I feel that everything goes wrong and nothing works,' (interview 12A).

The people with diabetes were afraid of long-term complications related to diabetes, especially losing their sight. They were also afraid that their children would develop diabetes.

Sometimes the people with diabetes felt that they were all alone with the disease, and that they would have wanted more support and understanding from their spouses. They hoped they could have more discussion about diabetes, its management, and worries connected with diabetes and future life. They also hoped that the family members would understand diabetes in greater detail. In addition, they expected motivation from their family members.

Diabetes being invisibly present

Diabetes was invisibly present in the family's daily life. The people with diabetes thought of it continuously, and they took it into consideration in everything during the day. They could not forget diabetes, and they had to think about blood glucose levels and their possible consequences. They must remember how much time had passed since they had last eaten or since they had injected insulin. They thought that diabetes restricted their life and, at the same time, the life of the whole family as well. Meal times must be regular, and the food must be healthy for the whole family.

'Such is life… searching for the place and time. One must always think of it,' (interview 15A).

Protecting the family's well-being

The people with diabetes wanted to protect the well-being of the family. They did not want to discuss diabetes, and they did not want the family members to worry because of them. The people with diabetes carried out their self-management routines unnoticed and did not want to trouble the family members by asking for help. They consciously avoided talking about diabetes, especially about the long-term complications. Every time someone talked about diabetes, they changed the subject. They also conveyed a picture of diabetes that was more positive than realistic. The well-being of the whole family was often more important for them than their own well-being.

'I don't want to talk about it in vain… because I don't want to be pessimistic about the future,' (interview 5A).

Family members variously contributing to self-management

The family members were concerned about the condition of the person with diabetes. In the course of the day, they called the people with diabetes several times to know how they were doing. In some cases, the spouses took care that the self-management equipment functioned properly.

'My husband wakes me up in the mornings and makes sure everything is all right,' (interview 13A).

The family members offered practical help with self-management as well. They injected insulin or performed blood glucose measurements. Occasionally, they reminded the person with diabetes to take their insulin or to check their blood glucose levels. Additionally, they could remind them of the importance of eating. The family members gave emotional support as well. The spouses listened and showed understanding. They also appreciated the opinions of the individuals with diabetes. The people with diabetes trusted in their spouses' help in many situations. The care shown by the whole family was considered important. The people with diabetes took

care of themselves, especially because of their spouses and children.

'So, I have to take care of myself so that I'm able to take care of the family,' (interview 6A).

Sometimes the family members were not interested in diabetes or blood glucose values, and they did not want to see self-management at all. They held themselves in the background and secretly kept an eye on the person with diabetes.

Learning to live with diabetes in the family

The people with diabetes were the educators of their family members. They told them the principles of diabetes treatment and advised them on how to inject insulin and how to check blood glucose levels. They also advised the family members on what they should do in the case of a hypoglycaemic episode. A few family members had had an opportunity to take part in patient training in the hospital or outpatient clinic.

Children were interested in the management of diabetes. They asked many questions about the self-management equipment and wanted to know if injecting insulin was painful. They played games where they imitated injecting insulin or hypoglycaemic episodes.

'When I'm eating, my daughter, now 3.5 years old, asks me if I have hypoglycaemia, and she likes sweets so much that, when she wants them, she says that her blood glucose levels are so down that she needs a candy bar,' (interview 2A).

In time, the whole family became used to diabetes, and it was rarely a discussion topic among the family members.

Discussion

According to this study, everyday life in families includes many different issues which affect the self-management of the adult person with diabetes, and *vice versa*. The support from family members is important to those with diabetes. Altogether, the family has an essential role in the everyday life of the people with diabetes, and it can also influence self-management.

Managing hypoglycaemia was perceived as essential in the family's everyday life. Hypoglycaemia was experienced as unpleasant, and people with diabetes kept their blood glucose levels high on purpose. The fear of hypoglycaemia affected self-management, which might be a barrier to achieving good metabolic control, as previous studies have shown.[16,20–23] When pursuing good metabolic control, it is important to take into consideration feelings and fears connected with hypoglycaemia.

The day-to-day self-management was visible in many ways in the family's everyday living. It was the responsibility of the people with diabetes and always on their minds. On the other hand, the management of daily routines took time, and self-management stayed in the background, as Safford *et al.*[24] also found out in their study. The time spent in self-management was approximately less than 1 hour. In the present study, finding the balance between self-management and the daily routines of the family was challenging.

Living with changing feelings was common among the people with diabetes. Stress, tiredness and depression connected with the management of diabetes have previously been found to be common among people with both type 1 and type 2 diabetes.[25] It is important to take into consideration the meaning of emotions and feelings,[1,26] because they may have an influence on self-management.[27]

Previous studies have shown the significance of the family in supporting self-management for children,[9] adolescents,[8] and adults with type 2 diabetes.[10,11] This study focused on adult people with type 1 diabetes. The family was described as contributing to self-management in many ways, such as providing reminders about self-management, offering practical help, and giving emotional support. On the other hand, the people with diabetes would have wanted more support and understanding from their families, and especially from their spouses. The people with diabetes tried to protect the well-being of the family by avoiding discussions about diabetes. They described that they were the educators of their family as regards the management of diabetes. The family members of adults with diabetes also needed education on the management of diabetes, and this must be taken into consideration.[28]

There are only a few previous studies on how children experience their parent's diabetes. Laroche *et al.*[29] interviewed adult people with diabetes and their children aged 10–17 years. According to the results, the children participated in taking care of their parent's diabetes by reminding them of, for example, eating and exercise. In the present study, new information was gained about how diabetes is seen in children's everyday life through their interest in diabetes and through their diabetes-related play, such as imitating hypoglycaemic episodes. However, further research is needed about how children experience their parent's diabetes.

In grounded theory, the aim is to collect data as rich as possible, and therefore many alternative sources of data are usually used.[17,19] In this study, the data were collected only by interviewing people with diabetes and their family members. On the other hand, the duration of diabetes was so long that the people with diabetes had plenty of experience of everyday life with diabetes. The data collection and analysis happen simultaneously in grounded theory research. In this study, the

themes in the interviews were based on what was discovered during the analysis of the previous interviews. The data collection continued until no new properties and dimensions related to the concepts were found.

The researcher must be aware of his/her biases and assumptions during the whole research process.[19] In this study, the primary researcher (first author) had professional experience about diabetes nursing, and consequently she was aware of her pre-understanding of living with diabetes. Memos were also written during the data collection and analysis.[17,19] To ensure the credibility of the categorisation, there were regular meetings with the co-authors during the research process.

The study participants' gender might have an influence on the everyday life experiences. Women usually took more responsibility for the family's daily routines and they might experience self-management differently from men. It is possible that the data would be different if more males were included in the study.

Rigour was ensured by using several strategies: firstly, the selection of the participants was specified; secondly, during the interviews, the participants' concepts were used to develop new questions for the next interview; and thirdly, the first author acknowledged possible preconceptions on the topic caused by previous professional experience. In addition, while presenting the findings, excerpts from the data have been used to support the findings.[17,30,31]

This study provides information about families' everyday life from the point of view of people with type 1 diabetes. When one wants to develop the individual care and education of adults with type 1 diabetes, it is important to take into consideration the everyday life in the family and the conditions in which self-management is performed. The family members, and especially the spouse, must be involved in the education of the person with diabetes, and the family members should also be provided with opportunities to discuss all kinds of feelings. The information gained through this study is valuable for developing education and for finding the best approaches to support adults with diabetes and their families in facing the challenges of living with diabetes.

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Declaration of interests

There are no conflicts of interest declared.

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