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Everyday life in a family of an adult person with Type 1 diabetes

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The purpose of this study was to develop a substantive theory of everyday life in a family with an adult with Type 1 diabetes. The data consist of interviews conducted with people with diabetes ($n = 19$) and their family members ($n = 19$). Based on the results, diabetes is visible or invisible, present in the everyday life. Life must be carefully planned and diabetes must be taken into consideration in everything. A person with diabetes tries to keep the balance with his/her self-management. Keeping the balance with self-management is demanding to a person with diabetes and the family members' support is needed. Managing with hypoglycaemia touches the everyday life of the whole family. The family lives with changing feelings. The family becomes acquainted with diabetes little by little and the process promotes the family's participation in the self-management. The family's contribution to self-management varies. Based on the results, it is recommended to develop family-centered interventions.

Keywords: Diabetes mellitus, Adult, Family, Substantive theory, Family nursing

Background

Diabetes is a common chronic disease all over the world. The aim of diabetes management is good metabolic control and the prevention of diabetes-related complications. The self-management has an important role in the management of diabetes. The person with diabetes does not live in a vacuum and the self-management of diabetes takes place in family's everyday life. It is known that family has an important role in the management of the diabetes.[1] Family members may provide practical help for day-to-day management of the diabetes as well as support and encouragement for adult people with diabetes.[2] People with diabetes perceive support from family members important in their self-management and the support from family members plays a role in optimising diabetes management as well.[1]

While family influences the self-management of diabetes, the diabetes of one family member also influences other members of the family.[1] Family members have worries of a different kind and fears, for example the fear of hypoglycaemia. They also perceive diabetes as a severe and burdensome illness.[3,4]

To find the best ways to support both the adult people with diabetes and family members, it is important to know what everyday life comprises and how the whole family experiences their life. The aim of this study was to develop a substantive theory of everyday life in a family with an adult person with Type 1 diabetes.

Method

The data for this study was collected by interviewing nineteen people with Type 1 diabetes and nineteen family members. Those family members were nominated by the person with diabetes. The grounded theory method was used to gather and analyse data. The grounded theory method is suitable when studying human action and interaction like the family's everyday life. The analysis followed the basic steps of grounded theory, starting with an open coding of the data, then followed by axial and selective coding.[5] The open coding was started by analysing every word and sentence, in order to derive substantive codes from the data. After that, substantive codes with similar contents were classified under preliminary subcategories. During the axial coding, the main focus was on grouping the subcategories into the main categories by constant comparison, by asking questions about the material, and by writing memos. During selective coding the core category was selected.

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. Written information about the objective of the research and consent form was given to the participating people. The permission to audio-record the interview was also asked.

Results

People with Type 1 diabetes were aged 28–65 years. The duration of diabetes ranged from two years to 58 years. Eighteen of them were female and one was male. Family members were spouses of the people with

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diabetes, including one wife and 15 husbands, and three adult daughters of the people with diabetes.

Based on the results *diabetes is visible and invisible present* in family's everyday life. There is self-management equipment all around the home, and during the days family members see the self-management routines many times. Invisible diabetes is present when it is in thoughts. You have to keep it in mind and plan the day-to-day living carefully for meeting the daily demands of diabetes. Life must be scheduled and it is impossible to do something spontaneously. Many things must be taken into consideration and sometimes diabetes seems influence invisible everything in life (see Figure 1).

One issue in everyday life is *keeping the balance with self-management*. The person with diabetes is responsible; she/he solves the problems and makes decisions connected with the management of diabetes. In addition she/he performs the concrete self-management. However, she/he shares the responsibility with family members. For example, spouses negotiate connected to the doses of insulin and other self-management routines as well. Still, the self-management is sometimes very demanding, it takes time and the results are not good enough. The family members see the self-management routines but sometimes the person with diabetes follows the self-management regimens so invisible that the family members do not notice them at all.

> *injecting insulin, self-monitoring and so on, they are my everyday job* (interview 13A)

The second issue in everyday life is *the managing with hypoglycaemia*. According to the participants, the episodes of hypoglycaemia are quite common. Those are experienced unpleasant condition where one cannot control his/her actions. Both the person with diabetes and family member are prepared to hypoglycaemia many ways. They keep sweets with them all the time, and all over the home there are fast-acting carbohydrates, just in case. Family members had learned to identify the symptoms of oncoming hypoglycaemia even earlier than the person with diabetes. The people with diabetes mainly took care of hypoglycaemia by themselves. They think that seeing hypoglycaemia is scary for the family members and especially for children. The people with diabetes also try to avoid hypoglycaemia and they keep their blood glucose level high on purpose, for example they eat more than needed or inject insulin less than needed, in addition they performed blood glucose measurements several times during the day. They do so, because they want to perform the daily routines in a family.

> *and when I start to behave cranky, they (family members) give me some sweet, they have learned to do so.*. (interview 9A)

> *I have to do dish, sort out the house, do the laundry, there is no place to the hypo*

Managing with hypoglycaemia makes the self-management challenging. It is not so easy to avoid hypoglycaemia and at the same time try to keep the good

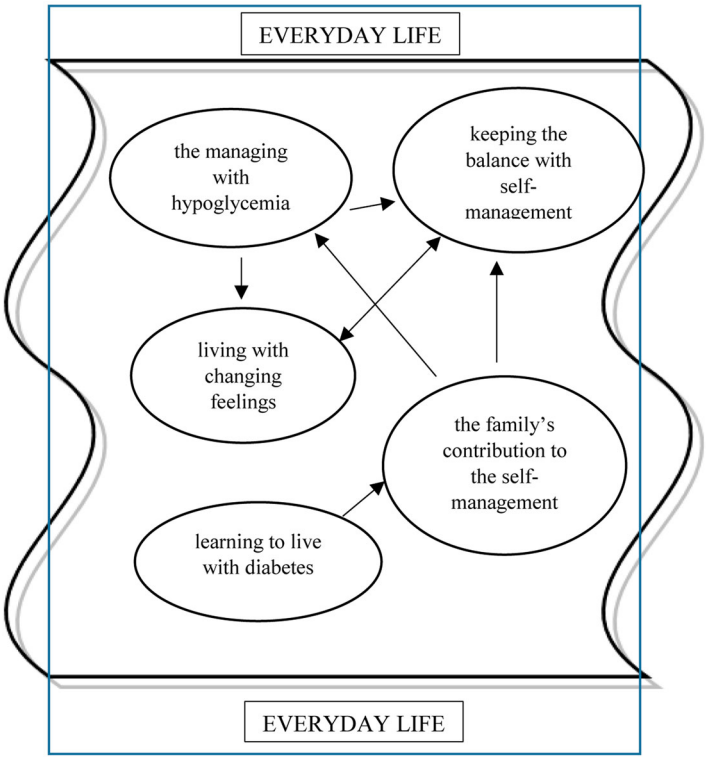

Figure 1 The visible and invisible presence of diabetes.

metabolic balance. In addition it causes fears among the family members and in a fact among people with diabetes as well. So the *living with changing feelings* is one part of everyday life. There are different kinds of fears, the fear of hypoglycaemia, the fear of long-term complications and even the fear of death. Feelings changed from happiness to sorrow or from satisfaction to dissatisfaction. Some days are full of worries and fears; some days are full of peace and confidence. The fear of hypoglycaemia is often described. The fear of long-term complications was common as well. Family members experience uncertainty; they do not know how to help the person with diabetes. Sometimes the whole family lives like on an emotional roller-coaster. The people with diabetes say that blood glucose levels affect their mood. When the levels are high, they are nervous and depressed. This affects the whole family as well. Living with changing feelings makes the self-management sometimes challenging.

> *there are so many risks, there is no knowing the future, we all are afraid* (interview 6B)

> then my wife had weird symptoms and I did not know how to help her! (interview 11B)

The family's *contribution to the self-management* is important part of everyday life. On the other hand family members offer concrete and practical help, for example they inject insulin or make blood glucose measurements. They also give emotional support to the person with diabetes. Family members are and they want to be involved in the management of diabetes. On the other hand family members are silent and watch the self-management routines from the sidelines. They do not participate in the management of diabetes. They also feel themselves left out. Sometimes family members do not want to see self-management or do not want to discuss diabetes. One person with diabetes told that the diabetes is like a taboo in their family, they have to avoid talking about diabetes. The family's contribution is important to the person with diabetes and it makes easier to keep the balance with self-management.

> *I know this is my responsibility, still the support from my husband is priceless* (interview 18A)

Learning to live with diabetes is a lifelong process. The whole family learn what kind of disease diabetes is and how to treat it. Unfortunately, the person with diabetes is often the only diabetes educator of family members. They told family members the principles of diabetes treatment, for example how to inject insulin or how to make blood glucose measurement. Learning to live with diabetes concerns little children of the family as well. They play diabetes-related games, for example they imitate injecting insulin or they imitate hypoglycaemia when they want some sweet. Little by little the whole family know more about diabetes and feel confident. They feel their life is normal and similar to the others'. Learning to live with diabetes makes the family's contribution to the self-management easier.

> *Our four years old daughter said that she is needing sweet because her blood glucose is very low* (interview 2B)

Discussion

In summary, the diabetes is present in the whole family's life in many ways. Everyday life includes many different diabetes-related issues which are visible or invisible. Diabetes seems to be always present. The whole family's everyday life must plan carefully for meeting the daily demands of diabetes. It is impossible to do something spontaneously. Experiences of everyday life are individual; nevertheless, it is important to remember the effects of diabetes on the whole family. It is recommended to pay more attention to the whole family in diabetes management.

The person with diabetes is responsibility for the self-management. However, the meaning of the family is important for an adult person with diabetes. Family members are involved in the treatment of diabetes which affects the self-management of the adult person with diabetes. The concrete help and emotional support from family members is crucial for the adult person with diabetes. That is why the family members need the education and support as well.

The managing with hypoglycaemia was one issue in family's everyday life. As previous studies have been shown,[6,7] the fear of hypoglycaemia affected the self-management, which might be a barrier to achieving good metabolic balance. Therefore, it is important to take into consideration fears connected with hypoglycaemia when targeting a good metabolic balance. We should encourage the whole family to discuss fears connected to hypoglycaemia. We should also provide accessible opportunities for discussions of that kind.

The family's everyday life consists of different feelings. Stress and depression connected with the management of the diabetes have been found to be common among people with both Type 1 and Type 2 diabetes.[8] It is important to take into consideration the meaning of emotions and feelings[9] because they may have an influence on the self-management.[10]

The family's contribution to the self-management is crucial and they need education connected to the treatment of diabetes as well. They must be involved in the education of the person with diabetes.[11,12] We should develop family-centered interventions, for example education and health-care services to the whole family. In addition we should provide different opportunities to discuss feelings and fears for the whole family. The feelings and experiences of the children of parents with diabetes should also be taken into consideration.[13]

The information gained through this study is valuable for developing education and for finding the best approaches to support adult people with diabetes and their families in facing the challenges of living with diabetes.

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