

Having control over type 2 diabetes means daring to be free

Anna-Greta Mamhidir and Berit Lundman

ARTICLE POINTS

1 Insight about having the primary responsibility for management of diabetes creates emotional strain.

2 If people with diabetes learn about their body's reactions they feel more secure.

3 Personal choice in everyday life is emphasised at the same time as feelings of guilt.

4 Willpower and a positive view of life make it easier to find a lifestyle.

5 Confirmation without blame is important for a reciprocal interaction between diabetes nurses and people with diabetes.

KEY WORDS

- Type 2 diabetes
- Control
- Freedom
- Education
- Interaction

Anna-Greta Mamhidir is from Primary Health Care Administration Hälsingland, County Council of Gävleborg; Berit Lundman is from the Department of Nursing, Umeå University.

Introduction

In this article we describe the process of assuming control from the patient's perspective. A qualitative study into the meaning of control and freedom of people with type 2 diabetes was conducted. Insight into the responsibility and loss of freedom that diabetes entails created emotional strain, but learning to know the body's reactions and how to test blood glucose gave a feeling of security. Participants emphasised personal choice in everyday life at the same time as feelings of fear and guilt about lapses in self care. A positive view of life made it easier for people with diabetes to find a suitable lifestyle and establish a feeling of freedom. An encouraging approach to caring for people with diabetes helped to build self-confidence and freedom.

Living with diabetes has been described as a balancing act (Ternulf et al, 1987). Learning to balance involves the decision to assume control (by knowing the body's response and learning how to manage the disease in daily life) and fostering supportive, constructive relationships (Paterson et al, 1998). Ideally, the education of people with diabetes should equally emphasise the importance of good blood glucose levels while maintaining a high quality of life (Lundman et al, 1988a; Anderson et al, 1995).

Method

A study was designed to establish the meaning for people with type 2 diabetes of having control over their disease and their life situation.

Participants

The study included two men and two women aged 42–65 years, with type 2 diabetes. The duration of the disease varied from 2–18 years. Participants were Swedish speaking and judged by the DSN to be able to describe the meaning to them of having diabetes.

The first four people who met the inclusion criteria were invited to participate in the study. Each person was informed by telephone about the purpose of the study. Three of the interviews were held in the participants' homes. One interview was carried out at the first author's workplace.

Interviews

A narrative interview method (Mishler, 1986) was used; the interview situation is illustrated in *Figure 1*. Using this method the meaning of experiences can be clarified and communicated in language in the form of narratives (Ricoeur, 1976). The participants were given the opportunity to talk freely about their experiences without being guided by any questions. Participants were initially asked to talk about situations in which they felt that they have control over their diabetes and life situation. During the course of the interview, a few clarifying questions were asked about what the interviewee had just said. The tape-recorded interviews were transcribed verbatim.

Analysis and interpretation

A qualitative method of analysis inspired by the philosophy of Ricoeur (1976) was used. The method was developed for nursing research at the Department of Nursing, Umeå University, and at the University of Tromsø. Söderberg et al (1999) and Rasmussen et al (1997) among others have described the method. The interpretation process includes three steps: the first reading; thematic analysis; and interpretation.

First reading

Each interview was read and summarised to

attain an understanding of the person's experience of having control in their life situations. The text was read several times to gain a feeling for the interview as a whole.

Thematic analysis

The second step, thematic analysis, was carried out according to the following three stages:

Stage 1

'Meaning units' that corresponded to the purpose of the study. A meaning unit may be parts of a sentence, whole sentences or whole paragraphs of text. The texts of each interview were analysed individually.

Stage 2

The meaning units in the different interviews were put together, organised and given labels. These labelled sentences were abstracted into sub-themes.

Stage 3

The text was studied to find meaningful patterns and relationships. All sub-themes were interpreted and grouped so that themes could finally be constructed.

Interpretation

The first reading and the thematic analysis were jointly interpreted through which a new understanding of the text came about (Ricoeur, 1976). The new understanding was discussed in relation to relevant research.

Results

The first reading indicated that the onset of diabetes resulted in a great change in lifestyle. The insight that patients had about the necessity of changing their lifestyle created emotional strain. Living with a long-term illness that can cause difficult complications created fear, stress, anger and a feeling of being out of control. A positive view of the future made it easier to find a suitable lifestyle and donated a feeling of freedom. Encouragement and support without blame were felt to be necessary for managing problem solving in everyday living. Ambivalence was expressed in the narratives as the desire to both 'live life as usual' and living according to what is best for the disease. The most striking finding



Figure 1. Well-accomplished interviews provide a base in diabetes care

was the participants' insight of their own responsibility, and that this insight seemed to be a kind of turning point.

Thematic analysis

Five themes were identified in the thematic analysis, which are described below with quotations from the interviews as illustrative examples.

Insight about having the primary responsibility for self-management of diabetes and the loss of freedom was painful and created emotional strain

The onset of diabetes was experienced as painful and stressful in terms of the great personal responsibility and loss of freedom that it entailed. Having a chronic illness was related to feelings of stress, anger and sorrow over something that would never disappear and at having lost a former lifestyle.

'...having diabetes is obviously a stressful thing...you can't get away from that...it's a burden to have to take care of it yourself...to have to take all of the responsibility yourself...'

Feelings of hate and anger were described at the onset of the disease when the patient faced the fact that he or she had a disease that would remain for the rest of his or her life.

'...it takes time to get used to it...it's like grieving...that this is generally how it's going to be always...'

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2 The first reading indicated that the onset of diabetes results in a great change in lifestyle.

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4 Feelings of hate and anger are described at the onset of the disease when the patient faces the fact that he or she has a disease that will remain for the rest of his or her life.

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1 It is important for people with diabetes to have a good understanding of the relationship between food, insulin and exercise.

2 Fear of complications was expressed when patients had diabetes for a longer time period and when they had been neglecting their self-management.

3 A positive view toward life can give a feeling of control.

4 Feeling well and having the right to make choices were emphasised by the participants.

5 When it became necessary for the participants to use insulin they felt more free and independent.

Learning to know the body's reactions and how to self-monitor blood glucose gave a feeling of security

Knowing the body's reactions (from feeling symptoms of hypoglycaemic episodes to symptoms of high blood glucose levels) was important for feeling secure in everyday life. It is important for people with diabetes to have a good understanding of the relationship between food, insulin and exercise. Self-monitoring of blood glucose gave a feeling of security. Uncertainty, insecurity and discomfort came from not recognising the body's reactions or not having control over blood glucose levels.

'... to test my blood glucose gives me a feeling of security.'

Personal choice in everyday life was emphasised at the same time as feelings of fear and guilt

The importance of making choices and living life to the full were emphasised:

'...I can go to a pub if I want...so I want to live life to the full...in the beginning...I was careful and restrictive...and I thought it was probably best for me to listen...I feel just as well...maybe better if I can live in my own way. Even if I knew that it would shorten my life by a year...living like I do now...I'd do it anyway because I want to really live before I die.'

Fear of complications was expressed when patients had diabetes for a longer time period and when they had been neglecting their self-management. Worry about vision damage was helped when information was given that good control of diabetes reduces the risk of complications.

'You get scared...that something will happen...but my vision is almost better now than it was before...because I've been to the eye doctor and he said that I shouldn't change my eyeglasses until...well, the glucose was stable...but my vision is good now and I can drive without eyeglasses if I want...so that's nice.'

At the same time, there were feelings of frustration and 'guilt about not taking care of oneself' and this was described as 'knowing what to do but still not doing it.'

Willpower and a positive view of life made it easier to find a lifestyle and gave a feeling of freedom

Constant changes in medical instructions were described as being tedious. With the will and perseverance to try to manage the situation a person can do what is necessary to have as high a quality of life as possible. In this study, it seemed to depend a great deal on each individual's readiness to take the initiative, act and take responsibility. A positive view toward life gave a feeling of control.

'...you can eat almost everything...it's just that you have to try to avoid some fatty foods and things like that...well, you have to eat vegetables.'

'...it's really up to you yourself to find the way you're going to live.'

Feeling well and having the right to make choices were emphasised by the participants. Not seeing diabetes as a disease, but something that a person has to live with, was expressed in the text in the following way:

'I don't look at this like a disease...this is my life.'

When it became necessary for the participants to use insulin they felt more free and independent:

'I travel...around the country...even outside the country...you have to be a little careful when you go out and eat...you have to choose...it's better...since I started using the needles (insulin)...I can take a little extra if I need it. I can plan.'

Confirmation without blame was important for reciprocal interaction

Patients described how diabetes care functioned about 20 years ago, and how patients met different doctors. It took a number of years before they met the diabetes nurse, which meant that the patient himself had to gather information about the disease. The patients reported that today's diabetes care offers better initial support at the onset of the disease.

'...I had had diabetes for at least 3 years

before I got to meet a diabetes nurse...what I learned about the disease I learned myself...and on my own initiative...you hear now that they have group-sessions and things like that...that seems ideal...so it has improved. They get another kind of start.'

The participants described the contact with the diabetes nurse and doctor as being good. They expressed feelings of having received valuable support on arrival to the health centre and meeting with the DSN. Patients felt that the DSN was there when things were out of balance. The dialogue and the understanding between the DSN and the patient was seen as important:

'They should be open people...the kind that understand a person...yes, just like that one...she sits there and jokes with me...and so it doesn't feel hard at all to go there either. I don't have to be afraid to tell her things...'

It was important for people with diabetes to have a functioning and honest relationship with the DSN and doctor:

'I can call her whenever I need to...but otherwise she calls me...when she understood how I was feeling...she called all the time...I saw through it...she was trying to give me support...she was fantastic. My husband asked, how much time does she have for you?'

'The nurse has to stop pointing her finger...because I think that everybody thinks it's hard when somebody points their finger.'

Interpretation

People with type 2 diabetes felt in control if they developed an insight into living with a chronic disease. Although participants may have felt physically well, they were aware about their responsibility and the restrictions on freedom. The meaning of living with diabetes was associated with pain over losing a previous lifestyle and being forced to live a strictly balanced life.

There was a feeling of reconciliation with the disease, which facilitated the individual's ability to find his or her own lifestyle. Once an individual chose a lifestyle they felt in control and free.

Control also involved the approach of DSNs. DSNs who did not moralise and blame the patient, but did indicate that they were always there for the individual had a great effect on self-confidence and helped patients to reach their own inner strength.

Reflection

The purpose of the study was to increase our understanding of the meaning of having control over diabetes and life situations among people with type 2 diabetes. The results showed that the participants' realisation that they had developed diabetes and had to live with it (and any potential complications) for the rest of their lives was painful. Everyday life was affected by a loss of spontaneity and uncertainty. The participants had feelings of stress, anger and sorrow as their present existence was threatened and they understood that some change in lifestyle was necessary in spite of the fact that they felt well.

The study confirmed that once participants had reconciled with the new situation it was easier to find the strength to handle new circumstances and search for a lifestyle of their own (Ellisson and Rayman, 1998). Demands for a regular daily life that include changes in eating habits, suitable forms of exercise and testing blood glucose have been described in other studies as one of the greatest difficulties in living with diabetes (Lundman et al, 1988b; Glasgow et al, 1989; Klepac, 1996).

Normalised blood glucose levels protect against hypoglycaemia and delay or even prevent later complications. Although diabetes is manageable and patients may feel that they have found their lifestyle, the illness still exists and, with it, the constant demand to keep blood glucose levels stable (Ternulf et al, 1987).

Daring to be free

The approach of DSNs is important for a patient's self-confidence and for mobilising their inner strength. If people with diabetes are given the opportunity to actively participate in decisions about their treatment, their self-confidence

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3 People with type 2 diabetes feel in control if they develop insight into living with a chronic disease.

4 The results showed that the participants' realisation that they had developed diabetes and had to live with it (and any potential complications) for the rest of their lives was painful.

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1 Entering into a partnership in the diabetes team is considered important and means that individuals actively participate in their own treatment.

2 If the person with diabetes is not seen as a member of the team, they can distance themselves from the healthcare system, which can be seen by the caregiver as non-compliance.

3 DSNs should be skilled in both medical and technical areas and to be competent teachers in educating their patients about diabetes self-management

4 Individuals must be given the chance to make their own choices regarding their diabetes care and their everyday life.

grows and they dare to be free in everyday life. This freedom can only exist if healthcare professionals avoid moralising and finger pointing when they meet with people with diabetes. Entering into a partnership in the diabetes team is considered important and means that individuals actively participate in their own treatment (Coulter, 1997). If the person with diabetes is not seen as a member of the team, they can distance themselves from the healthcare system, which can be seen by the caregiver as non-compliance. This has to do with a desire to have control over one's own life and to be involved in the decisions that must be made in taking care of oneself (Ellison and Rayman, 1998).

DSNs should be skilled in both medical and technical areas and be competent teachers in educating their patients about diabetes self-management (Callaghan and Williams, 1994). Rodwell (1996) has discussed patient empowerment as the force that qualifies the patient to participate and make decisions. This in turn allows the patient to become aware of his or her own strength and ability and at the same time involves sharing power, self-respect and respect for others.

Conclusions

Individuals must be given the chance to make their own choices regarding their diabetes care and their everyday life. At the same time, the participants of our study indicated that the knowledge and support of DSNs were of vital importance. DSNs should be available according to each individual's needs, and it is these that determine what type of knowledge or support is required. Our interpretation is that an approach to diabetes care that encompasses openness, sensitivity and respect leads to a feeling of encouragement and builds self-confidence of people with diabetes. ■

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