



Perception and integration of people living with type 1 diabetes – an empirical study

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Introduction

The chronic complications of type 1 diabetes impose a heavy physical, psychological and social burden on people living with the condition. Good metabolic control reduces the risk of developing chronic complications¹ and could lead to an improved well-being for people with diabetes.

As the illness has an impact on all areas of life, coping with diabetes and achieving good metabolic control are not always easy tasks for people living with diabetes. People with diabetes have to make daily decisions concerning the illness which influence their physical, social and psychological well-being. These decisions involve health-promoting behaviours such as measuring blood glucose whenever necessary and taking the appropriate amounts of insulin.

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Abstract

Background: The chronic complications of type 1 diabetes impose a heavy physical, psychological and social burden on people living with the condition. Improved metabolic control reduces the risk of developing chronic complications and could lead to improved well-being for people with diabetes.

Aims: The aim of this study was to explore the perceptions of adults with type 1 diabetes who have improved their metabolic control with respect to acceptance, knowledge, social support and their relationships with healthcare providers.

Methods: The study included ten people with type 1 diabetes who had achieved and maintained a reduction of 1.5% in their HbA_{1c} during a one-year period. A phenomenological qualitative semi-structured interview was used in the collection of information from the participants. The interviews were analysed using the method of meaning condensation; these were interpreted from a perspective of integration.

Results: The study shows differences among people living with diabetes regarding their perceptions of living with the condition. The people have at least three different strategies of integrating diabetes, based on their perception.

Conclusions: Integration is a life-long process and in this process, the person with diabetes has to learn to integrate diabetes into both behavioural and psychosocial aspects of life.

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Key words

Type 1 diabetes, perception, integration, improved metabolic control, complications, qualitative study

Several studies suggest that the ability to accept diabetes has an impact on coping with the illness.^{2–6} Access to knowledge of diabetes and the ability to actively implement this knowledge are a part of determining whether or not a person is able to maintain good control over their diabetes.^{2,5,7,8} However, the relation between a person's self-reported ability to cope with diabetes and their HbA_{1c} levels is not always consistent.³

Collaboration between the person with diabetes and healthcare providers might help to achieve good metabolic control. Factors that are important in developing a relationship of trust between people with diabetes and healthcare providers include the work of competent professionals who address a person's specific situation,^{2,4–6,8,9} and continuity of care.¹⁰ Having a good

relationship with healthcare providers makes it easier for a person with diabetes to discuss the way day-to-day psychosocial problems impact on living with diabetes. It is important to acknowledge the person behind the condition and respect their individual diabetes-related choices and responsibilities.^{4,7,11} If healthcare providers are unaware of the importance of a relationship built on trust and respect, an unnecessary extra burden is placed on the person with diabetes.¹²

Most people with type 1 diabetes with good metabolic control feel that their relationship with healthcare providers is good. On the other hand, most people with poor metabolic control feel that they have a poor relationship with the healthcare providers.⁹ The social network is important in coping with diabetes: well-educated people and



those with a family or strong social network tend to achieve good metabolic control. This reflects the importance of involving the social environment in active support for people with diabetes.^{4–11,13}

Theoretical framework

Theoretically, this study is inspired – and to some degree structured by – a modified version of *Adapting to Diabetes Mellitus: A theory Synthesis* by Robin Whittemore and Sister Callista Roy, which derives from The Roy Adaptation Model¹⁴ and The adaptation to Chronic Illness Model by SE Pollock.¹⁵ This includes the structure of the interview guide and analysis. The adapted model is presented in Figure 1.

The figure describes living with diabetes as ongoing stimuli that require a person to make decisions that are important in coping with their illness on a daily basis. The way in which living with diabetes is perceived influences the extent to which a person is able to integrate the condition into different areas of life. According to Roy and Whittemore, people must recognise the demands and restrictions of diabetes in daily life, and take ownership of their diabetes. If people are able to choose health-promoting behaviours to maintain or achieve good metabolic control, their HbA_{1C} levels will be stabilised, thus lowering their risk of developing complications. It is therefore of interest to determine whether people react in the same way regarding the perception and integration of diabetes.

Aim

This article describes a theoretically inspired qualitative research project that aims to explore, in adults who have improved their metabolic control, perceptions of acceptance, knowledge, social support and relationships with healthcare providers.

Sex (N)	Age (Years)	Duration of diabetes (Years)	Highest HbA _{1C}	Lowest HbA _{1C}
Female (5)	38.4 (23–47)	25.6 (10–33)	11.2% (9.3–13.5)	7.5% (6.5–9.4)
Male (5)	54.6 (41–71)	33.8 (24–49)	10.9% (9.3–11.6)	8.0% (6.8–9.6)

Table 1. Data on participants – mean value and range during study period

Patients

The study focuses on people with type 1 diabetes who have achieved a decrease in their HbA_{1C} of 1.5% during a one-year period, and who have maintained this level. HbA_{1C} was above 9% at baseline. Data on HbA_{1C} levels three years prior to inclusion in the study was collected from the participants' medical records.

The decrease in HbA_{1C} indicates a change in behaviour and/or in perception which is significant for obtaining good metabolic control and preventing long-term complications.

The participants were consecutively chosen from laboratory samples derived from all type 1 diabetes patients (n=3000) attending the Steno Diabetes Center in Copenhagen, Denmark. Fifteen people with type 1 diabetes over the age of 21 years who had been living with diabetes for more than three years (eight women and seven men) were asked in writing to participate in the study. Ten people gave their consent and were included in the study. Consent from the Ethics Committee was not necessary for this study, since the patients did not participate in any bio-medical intervention. Table 1 shows data on the participants during the study period.

Method

This explorative research is a theoretically inspired, descriptive, retrospective study. A phenomenological qualitative semi-structured

research interview inspired by Kvale¹⁶ has been used for collecting information from the participants.

An interview guide covering the principal topics derived from the background section, such as the perception of acceptance of diabetes, knowledge, social network and relationship to healthcare providers, was used. To ensure rigor in the analysis, a limited number of topics were chosen in the interviews. These were also chosen to ensure that areas were covered during the interviews that are of relevance to investigating people's perceptions concerning improved metabolic control^{16,17} (Figure 2).

The semi-structured interview was selected as a research method in order to give people with diabetes an opportunity to describe their personal experiences and reflections concerning achieving improved metabolic control. The interviews were conducted during the spring of 2003 by the first author of this article. The interviews lasted between 35 and 90 minutes and were recorded on audio-tape and transcribed verbatim before the analysis.

Analysis

The interviews were analysed using the method of meaning condensation described by Kvale.¹⁶ The text was read thorough several times to get a general sense of the content. It was then divided into the content areas emerging from the themes of the interview guide; the answers



were compared and searched for differences and similarities. The interviews were interpreted from a perspective of integration, based on the modified version of 'Adapting to Diabetes Mellitus'. The main topics of the analysis were then condensed into a description of the findings and, thus, the participants were categorised into three groups.

Results

According to Roy and Whittemore, the perception of illness is the key to integrating diabetes into different areas of life.

The analysis describes three different types of coping strategies concerning the perception and integration of diabetes in improving metabolic control. These will be presented in the following:

Developing perception: people who integrate

Three women belonged to this group. Their perceptions had developed over a long period of time. The women described the process of integrating diabetes in their everyday life as 'before and after'.

In this group, people tended to have changed behaviour in relation to diabetes, inspired by a change in their perceptions of the condition.

They had developed a level of perception at which they were able to speak about their illness quite openly with professionals, friends and family. This change in perception came about in different ways.

One of the women had not seen a diabetes specialist for several years; she saw a new general practitioner who insisted on her visiting a specialist. This helped her in the process of accepting that she had a chronic illness.

She describes the process in the following way:

'I can meet people face to face now. If I feel unwell, I can call my doctor and ask him to take a look at

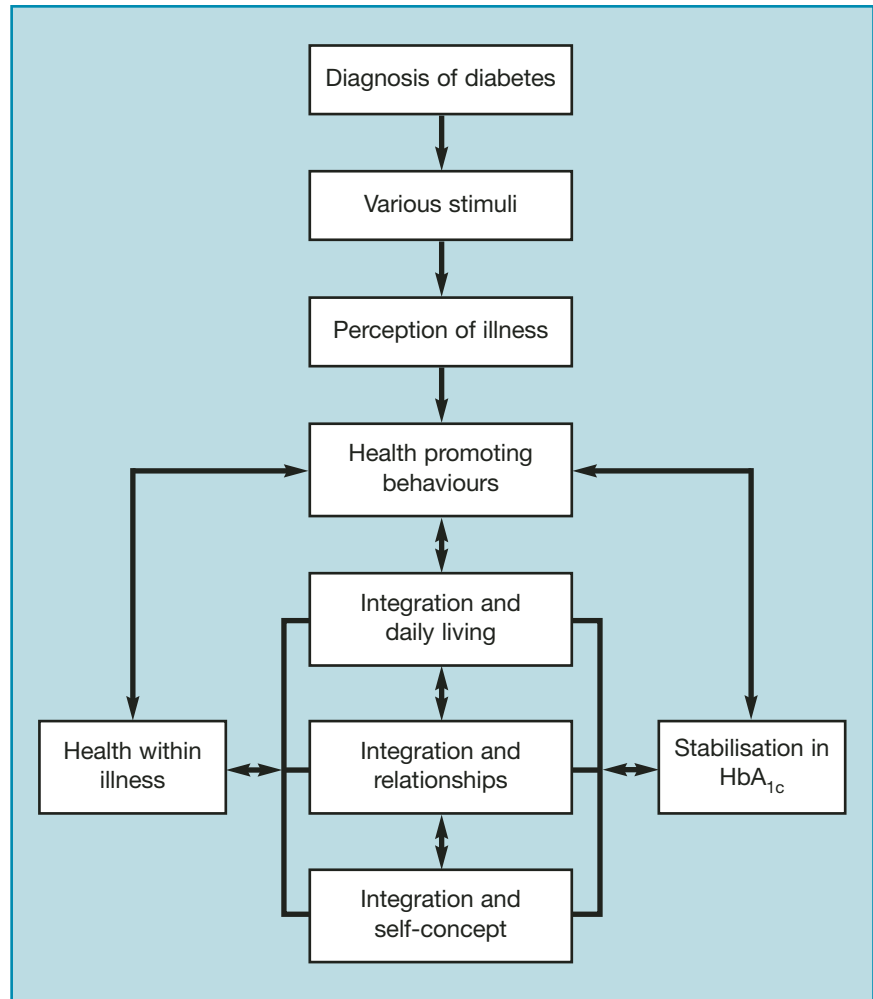


Figure 1. Modified after Robin Whittemore and Sister Callista Roy: Adapting to Diabetes Mellitus: A Theory Synthesis, *Nursing Science Quarterly* 2002; **15**: 316

me. I never used to do that before because he would find out that my diabetes was a mess. I can talk to my friends and my husband in a different way because now I am doing something about my diabetes, and that is important. If you are not doing anything, you feel like you can't talk to anyone about it. As soon as you start doing something, you can ask other people for help and talk to them about it. You can't talk about it when you are neglecting your diabetes because you don't want anybody to know.' (Female, 47 years)

People who manage to integrate feel a positive change in self-concept, as well as in their relationship

with their environment. One of the women experienced this change in perception parallel to entering into a new relationship, which provided her with social support to accept her diabetes:

'...a couple of years ago I slowly but surely started to accept my diabetes (...) this was about the time I started dating my boyfriend.'
(Female, 23 years)

The women also experience improved relationships with their healthcare providers. The third woman in this group had a consultation with a dietitian, who was able to identify one of the major problems influencing her perceptions:



Main topic 1: Acceptance
 Could you describe your experience of living with diabetes?
 Do you feel that you have accepted your diabetes? How does that affect you?
 Do you feel that your daily life is influenced by the fact that you have diabetes? Has this changed in recent years?
 Do you consider yourself a sick person or a healthy person?
 Does having diabetes put any limitations on your life?
 Do you feel dependent on other people?
 In what ways has the decrease in your HbA_{1c} influenced your daily life?

Main topic 2: Knowledge
 How do you use your knowledge about diabetes in your daily life?
 Have you been seeking information about diabetes in different fields?
 How do you manage unforeseen situations?
 What do you consider to be good metabolic control? Has this changed in recent years?

Main theme 3: Social network
 In what ways have your family or environment been involved in your improvement of metabolic control?
 How are you influenced by other people's reaction to your diabetes?
 What is the significance of having diabetes in your relationship with others?

Main theme 4: Relationship with healthcare providers
 How would you describe your relationship with healthcare providers?
 In what way has the improvement of your metabolic control affected your relationship with healthcare providers?
 Have you experienced support from healthcare providers during the process of improving your metabolic control?
 Which group of healthcare providers have you consulted during the past years?

Figure 2. Interview guide

'For the first time in years (...) I talked to a dietitian with whom I had a good chemistry (...) I felt that she immediately understood my problem concerning eating several times a day (...) I understood that I had some options and then in a way it became more acceptable to eat.' (Female, 36 years)

In this group we can talk about a certain 'dialogue' between

diabetes, the everyday demands of the illness, and the people. This gives rise to further dialogue with family, friends, healthcare providers, etc. The women were able to relate in a new way the knowledge they gained about their illness to their life.

One example was expressed in the following way:

'I feel better now about coming to the outpatient clinic than I did

before because I realise that it's for my own benefit that I talk to the doctor and get my test results. With these, I can choose to either change something or not.' (Female 23, years)

Taking ownership over diabetes motivated the women to develop coping strategies in all areas of life. The dialogue with the demands of diabetes gave the women a greater sense of flexibility in choosing various health-promoting behaviours.

Having improved their metabolic control, the women felt a positive improvement in their well-being.

Consequence-based perception: people who compensate

This group consisted of three men and two women. These people have developed diabetes complications and experienced the consequences of these complications in their everyday life. These consequences changed their perception of living with diabetes. They developed an ability to relate to the evolving complications and the consequences of these. This group is characterised by people who, primarily on an unconscious level, tended to base their perceptions and reactions on a risk-minimising strategy; they tended to be reacting to complications. One side of reacting means that the people integrated their knowledge about their illness. One woman describes her experience in this way:

'I never used to measure my blood glucose before. I just injected the insulin and had something to eat. But since I developed some complications and received more knowledge I have become more attentive.' (Female, 45 years)

Decisions concerning health-promoting behaviours were chosen in an attempt to compensate for the consequences of complications, and were thus dependent on the



impact of the complications in their everyday life.

Because no personal benefit was perceived in using these strategies, the people who compensate did not feel that the coping strategies made their life more flexible. One of the men describes his reflections like this:

'I think it would affect my everyday life too much if I had to measure my blood glucose all the time to see if it was too low or too high.'

(Male, 41 years)

These people's relationships with the environment and the healthcare providers did not change. They were not particularly aware of recommendations from healthcare providers before the complications occurred – as expressed by a 48 year-old man:

'For as long as I can remember, the doctors have been going on and on about having to improve my HbA_{1c}; I never used to take that very seriously because I was generally doing fine.'

Diabetes was not integrated in all areas of life and did not affect the people's self-concept or acceptance of diabetes. People who compensated did not experience improved well-being, in spite of improved metabolic control:

'I could see an improvement in my blood glucose readings (...) but not in my well-being (...). Even though my blood glucose has been high I was never ill from that.'

(Male, 71 years)

Stationary perception: people who maintain a distance

Two men formed the last group. The perception of these people, who maintained a distance, was stationary. We can say that in this group people decided to choose behaviours that minimised the impact diabetes had on their daily living.

In this case, a man almost tries to forget his diabetes; he has not

accepted it, nor is it integrated into his life:

'I set goals and have visions for my company but not for my diabetes – that is just something I live with.' (Male, 52 years)

They did not speak a great deal with family or friends about their diabetes, and made use of a rather defensive strategy. One of the men expressed his perception of living with diabetes in relation to his social network in this way:

'I do not care to talk about diabetes. If people know you have diabetes they think they need to say good-bye properly because they don't think they will see you again. I believe the focus on the seriousness of the illness is getting out of hand' (Male, 52 years)

These people maintained a distance regarding the daily demands of diabetes, and thus avoided choosing health-related behaviours that could draw more attention to their illness. As their illness was not integrated within their self-concept, they did not relate to advice from healthcare providers – or took this only partially. One of the men followed the advice of healthcare providers even though he did not know the reason behind it:

'I do not know why I was in the hospital. The doctor told me or asked me if I was willing to come for five days,' (Male, 61 years)

The other man expressed it in this way:

'Personally, I have chosen not to focus on cholesterol: it does not fit in with the things I like. I might focus more on blood pressure or something like that.'

Their perception of living with diabetes had not changed since they were diagnosed. In improving their metabolic control they used old coping strategies learnt years previously, and for the study period these strategies were sufficient to improve their HbA_{1c}. Thus, they have improved

their physiological status without integrating diabetes into their life.

The two men did not feel a change in well-being after achieving improved metabolic control.

Discussion

Choosing a modified theoretical frame of reference involving the concept of perception offered a theoretical focus for analysis. However, this limited the interpretation of the interviews. The strength of using interviews, a frame of reference, and having chosen a focus for the study, offered the opportunity to explore a phenomenological view of a small group of people living with diabetes – thus describing their experiences in achieving improved metabolic control. This could have been broadened by the use of observation and other objectifying methods. Other demographic status, or social similarities or differences may provoke the use of different types of strategies concerning the perception and integration of diabetes; but this has not been investigated in this study.

By being active in the field of nursing, the first author, on an unconscious level, brings in systems of everyday and professional thoughts that can function as non-reflected theoretical constructions.¹⁸ For example, the researcher might be blind to certain aspects and highlight others. In this study, discussions among the researchers (authors) and the use of interviews served as tools to reduce this kind of bias.

This study shows differences among people living with diabetes concerning their perceptions of living with the condition. The people had at least three different strategies for relating to diabetes, based on their perceptions. This explains the different bases for the ways in which the people related to the



topics of acceptance, knowledge, healthcare providers, friends, and family in the process of integrating diabetes into their life. This study describes the current status of the participants' level of integration regarding these topics; but it does not describe to what extent a person could move from one level of perception/integration to another. In a grounded theory study, Hernandez¹⁹ identified integration as playing an important role for a successful life with diabetes. She described integration as a three-phase process during which a person can move from one to the next. The three phases are named 'having diabetes', 'the turning point', and 'the science of one'. This process of transition can take years. The study presented in this article also demonstrates that integrating diabetes into a person's life is a lifelong process. Except for one person, the participants had an average duration of diabetes of 31.8 years, which shows that the process and its length are different for each person.

This study supports the idea that integration is an important aspect of living with a chronic illness – which was also found by Whittemore.²⁰ The results also support the idea that perception is a key to understanding the extent to which diabetes is integrated into a person's life. Perception is not a fixed mark, but changes throughout life. The study performed by Paterson and Thorne¹⁰ also found that to support people with diabetes in effective self-management, the healthcare providers must be aware that living with diabetes is itself a process.

Recommendations

This study is descriptive and can not provide direct recommendations for healthcare policy or healthcare providers. But the conclusion

indicates that perceptions of living with diabetes are of importance for integration. Integration is a lifelong process, and in this process the person with diabetes has to learn to integrate diabetes into both the behavioural and psychosocial aspects of life. The healthcare providers often pay too much attention to behavioural aspects and medical advice, which might actually prolong the process of a person taking ownership of his or her diabetes. On the basis of the findings in this study, as well as other studies (Thorne, Hernandez, Whittemore), it is recommended that the healthcare providers focus more on perceptions of illness and the psychosocial perspectives of living with diabetes in order to promote integration. This can lead to improved metabolic control.

Conflict of interest:

None

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