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ABSTRACT

Title. Learning to live with illness: experiences of persons with recent diagnoses of diabetes mellitus

Aim. The aim of the study was to reach a deeper understanding of how the first months of learning to live with diabetes mellitus are experienced by persons with the illness.

Background. The process of learning to live with an illness is complex. By better understanding the learning process for persons with diabetes in the early stage of the illness, the role of the health care can be shown.

Method. A qualitative descriptive design was used, and interviews were conducted.

Thirteen informants with a recent diagnosis of diabetes were included and asked to narrate about their experience of living with diabetes. Qualitative inductive content analysis was used.

Findings. Four themes emerged: ‘taken over by a new reality’, ‘the body plays a role in life’, ‘different ways to learn’ and ‘the healthcare service as a necessary partner’.

Conclusion. People with short-term experience of the illness gained knowledge through personal resources such as their own experience and self-reflection. The learning process includes an inner dialogue between the self, the body and the life. Informants were concerned with grasping a new reality and understanding a different self and body where lifestyle changes and uncertainty were present. When health care was accessible and sensitive to their needs, those with short-term experience of DM chose the staff as key players in the early stages of their life with diabetes.

Keywords: patient learning, patient knowledge, patient education, qualitative content analysis, daily life perspective, diabetes mellitus

SUMMARY STATEMENT

What is already known about this topic

- Persons with DM provide 99 % of the care themselves, and are responsible for the daily management of their disease
- Chronic conditions such as diabetes mellitus often cause illness and suffering that intrude on the patient's daily life. This implies the need for new knowledge, motivation and new skills.
- Learning in general is a well-known process but knowledge about the learning process in an unwanted situation like DM is absent from the literature.

What this paper adds

Understanding of the experiences of learning to live with DM over a short duration.

Aspects of the learning process of importance for meeting healthcare needs

A starting point in understanding the life-long learning involved in living with DM

Implication for practice and/or policy

Healthcare staff should grasp the opportunity to provide the motivated newly diagnosed patient with the knowledge and skills required.

Health care staff should be aware that sharing experience with others is not of interest for people newly diagnosed with diabetes mellitus

When healthcare is accessible and sensitive to a person's needs, patient with short-term experience of diabetes chose healthcare staff as their partner to trust in the early stages of living with diabetes.

Title

Learning to live with illness: experiences of persons with recent diagnoses of diabetes mellitus

Introduction

When an individual is diagnosed with a chronic illness, the life situation is changed. This implies a need for new knowledge, motivation and new skills (Rankin and Stallings 1996) for the development of an individual's personal adaptation to the new situation by learning to control the disease and treatment, relinquishing control and integrating the illness and illness-driven boundaries as part of a reconciled self {Aujoulat, 2008 #55}. Chronic conditions such as diabetes mellitus (DM) often cause illness and suffering that intrude on the patient's daily life. Persons with DM provide 99 % of the care themselves, and are responsible for the daily management of their disease (Charmaz 1983, Funnell and Andersson 2003, Funnell and Andersson 2004, Hernandez 1995).

The term *diabetes mellitus* describes a group of metabolic disorders characterized by hyperglycaemia caused by defects in insulin secretion, insulin action or both. The prevalence of diabetes in Sweden is about 3% (300.000–400.000 persons) (ISPAD 2006). Adherence and compliance are two aspects that are important in the person's ability for self-care connected to the illness (Friberg and Hansson Scherman 2005). Knowledge, or the process of learning development, involves aspects of what, how, when and why we learn or gain knowledge (Lave 1993, Marton and Booth 1997). The learning process, when successful, goes from a stage in which the individual lacks knowledge and skills to one of knowledge, attitudes and

skills, enabling the person to make considered choices and giving him/her confidence in problem solving. Learning has not only a cognitive

dimension but also an embodied, emotional and acting dimension grounded in the social and cultural situation (Rankin and Stallings 1996).

Learning is in general an ongoing process of which the person him/herself is more or less aware. Learning is also described as enjoyable since the capacity of human beings to learn is part of their ability to survive and develop. Merely by living, a person cannot avoid learning (Lave 1993, Marton and Booth 1997). Studies have shown that persons newly diagnosed with diabetes crave information and basic knowledge about the disease, which is necessary before they can learn to manage the illness (Dietrich 1996, Luyas 1991, Paterson and Sloan 1994, Tenulf Nylin et al. 1987). However, knowledge development and the learning process when a person has to deal with an unwanted situation such as a chronic illness is, as far as we know, poorly described in the literature. New and deeper understanding of how persons living with different stages of the illness experience the learning process is therefore needed. By identifying the learning process for persons with diabetes, even in the early stage of the illness, the role of the health care can be shown.

The aim of the study is to reach a deeper understanding of how the first months of learning to live with diabetes mellitus is experienced by persons with the illness.

Methods

Design

To understand the experience of learning to live with diabetes mellitus, a qualitative descriptive design was used and interviews were conducted (Kvale 1996).

Participants

The informants in this study were recruited from an endocrinological ward at a university hospital in a metropolitan area in Sweden. The informants were consecutively and purposively enrolled in the study. A selective sampling approach was used. Thirteen informants were chosen in a range of ages (26–65 years) and different genders (5 women, 8 men), social conditions (3 living alone, 10 living with partners) and working conditions (11 working, 2 not working), as including different life conditions increases the possibility of shedding light on the research question from various perspectives (Patton 2002). No consideration was given to whether the informants were diagnosed with type 1 or type 2 DM.

Data collection

As the lived experiences were of interest, open-ended interviews were chosen (Kvale 1996). Interviews took place in a setting chosen by the informants and lasted approximately 45 to 70 minutes. The informants were asked to narrate about their experience of living with diabetes with the open-ended question, ‘How have you experienced this first months living with diabetes?’ When it felt appropriate, the researcher asked, ‘How have you experience support during this time?’ and ‘Can you tell me about a situation where you took your diabetes into account?’ if these issues had not already been raised. Probing questions that clarified and explored their description were asked when necessary; e.g. ‘Could you tell me more about that?’, ‘What did you do?’ or ‘What did you feel?’ No definition was given of support or specific situations of interest; instead, the informants chose what they wanted to talk about. The interviews were audio-recorded and transcribed verbatim by the first author. The first author endeavoured to be structured, clear, kind, sensitive and open during the interviews (Kvale 1996).

Ethical considerations

The research was performed according to the ethical guidelines described by (Polit and Beck 2006), including the principles of justice, beneficence and respect for human dignity. The study was approved by the regional research ethics committee (Dnr 03-589). All informants were given both oral and written information about the study, confidentiality and the possibility to withdraw at any time without stating the reason. The interviews were number coded, and interview tapes and information on informants were stored in a secure cabinet.

Data analyses

Content analysis was used. This is a method well suited to analyzing data on multifaceted, sensitive phenomena such as lived experiences of a condition. Manifest, latent, deductive and inductive approaches can all be used {Elo, 2008

#1} on a variety of data and depths of interpretation (Graneheim and Lundman 2004). For this study a qualitative inductive approach was chosen. An approach based on inductive data moves from the specific to the general so that particular instances are observed and then combined into a larger whole or general statement {Elo, 2008

#1}.

There are different ways of developing themes from a text. For this study the process of analysis involved meaning units, condensed meaning units – description close to the text, abstracted meaning units – interpretation of the underlying meaning , sub-themes and themes (Graneheim and Lundman 2004). All of the interviews were first read through so that the researchers could grasp the material in its entirety. The researchers continued the analysis by gaining an understanding of the text through dividing the text into meaning units, which could

consist of words, phrases or sentences; in the next steps these were condensed and abstracted, compared, sorted and interpreted into sub-themes and themes.

All authors read the interviews; the first and third author performed the steps of the analysis and the second author read the analysis. All authors discussed the results until a consensus was reached. See Table 1 for an analytical overview.

Table 1 The analytic steps

Meaning unit	In the past I couldn't say no to anyone, I've always been so kind... Salesmen that turn up time and again ... things like that. Now I say no to them.
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Condensed meaning unit	Been too kind. Hasn't been able to say no but does that now.
Abstracted meaning unit	Prioritizes him-/herself.
Sub-theme	The self is allowed to step forward.
Theme	Taken over by a new reality.

Findings

Four themes were found that illuminated learning how to live with diabetes mellitus during the first months after diagnosis, namely 'taken over by a new reality', 'the body plays a role in life', 'different ways to learn' and 'the healthcare service as a necessary partner'.

Taken over by a new reality

Daily life was experienced differently compared to the life before the diagnosis. Another reality was presented and forced on the informants, including new priorities and various changes in lifestyle behaviour.

Earlier known situations now become unknown

Situations that had simply been part of daily life before the diagnosis had now become issues that needed to be taken into consideration. Going abroad, going to a conference with work or developing a stomach disorder suddenly demanded ‘a different way of thinking’, as one informant described it. The experience of having dinner as usual, and remembering that the insulin injection had been forgotten, made the diabetes noticeable. The informants experienced new needs for planning and preparation.

P12: For example, now when I’m going abroad, and then of course I have to find out if there’s something special that I need to think of... I mean you’ve got to take insulin with you just in case, so well it’s all this kind of thing that means you’ve also got to think and plan, which also takes a lot of your time, keeping one step ahead.

Being aware of one’s new limits was also experienced.

P13: I’m more sensitive to stress than I was before... feeling I have so much more than just sampling and injections to think about.

In the situations where the illness became an aspect to take into account, there were opportunities for taking actions, such as seeking information, trying a solution and evaluating it, or ‘going with the flow’ and seeing how it went.

P3: You just had to try and keep to the eating hours like at the hospital, but that didn’t work at all when I got the stomach disorder.

Sometimes the informants experienced that a certain situation would imply new demands, something could also happen that caused an awareness of that new conditions were needed.

The self is allowed to step forward

A focus on prioritizing oneself and listening to oneself was experienced as ‘being nice to oneself and listening to the signals I get’.

Listening to how the body felt and what was important for oneself became important.

P5: Because I need to focus on myself now too. Try to have a little more time for myself now as well.

External things could make it difficult, e.g. financial problems or heavy workload, but there was a clear aim to put oneself first.

The illness raises the need for concrete changes

The need for behavioural changes in ways of daily living was constantly present. The informants constantly evaluated their previous behaviours with the newly apparent conditions.

They reflected on which behaviours could be continued and which had to be changed. Even though they found that behaviours needed to be changed, they might also see this as impossible to carry out. The changes were of various kinds, e.g. type and amount of food, cooking, exercise, smoking and workload. The diagnosis itself was experienced as being a “wake-up call” that made them realize the need for changes. It also became easier to make changes that might have been recognized for a long time.

P5: So it’s been a real wake-up call, and now I’ve sort of changed everything so to speak, and I think it feels good. I make sure that I eat breakfast, which is something I haven’t done for about three years.

The acquisition of new knowledge might precede the lifestyle changes; however, the informants might already have had considerable knowledge but not been sufficiently motivated. Trying new habits implies new experiences in learning to live with the illness.

The body plays a role in life

From being a body that was familiar, the body turned into a new player in life with new dimensions and demands. The glucose meter was a valued tool for getting to know and understand the body and the illness.

The body shows itself

The body suddenly took an active part in the person’s life. Bodily signals or symptoms made the new body visible, and action had to be taken to satisfy the body.

P11: Shortly after I came home I could feel it, then I ate a banana and sat down. I felt as if I was going to faint. I don't normally feel like that. It was unusual – a bit hazy, I thought. And then when I'd been sitting down for fifteen minutes or so it was better. [person describes an experience of hypoglycaemia]

The body became a “new player” in one's life; it had to be listened to and needed to be focused on. The body gave permission and had to be taken into account in different ways than before. The body became more central for the individual.

The glucose meter as proof of the body condition

Glucose levels were measured to understand how the body worked and what influenced the glucose level. Measurements were taken to confirm signals, to make sure that what was expected was also what was measured. From an intensive initial period with frequent measurements, there was a development towards using measurements more in cases of uncertainty.

P7: So I notice that I feel quite well when the glucose is just a bit too low or a little too high – a vaguely unpleasant feeling... if I go over 10–11, something like that, then I feel a different kind of discomfort, and it's seldom wrong that I feel that and take the glucose. It's either one of them [low or high glucose level].

The glucose meter was experienced as a tool giving insight into how one's body works, increasing the feelings of security and control.

Different ways to learn

Obtaining, understanding and using information was complex, but this provided new knowledge as well as reflection on one's experience. It also raised a number of questions. Uncertainty was a dominant feeling due to the new situations and demands.

The complexity of knowledge

Knowledge was experienced as being desired but also new, changed and confirmed. Knowledge was also experienced as not reliable.

P13: I'd like to know more, learn more about how it works to get better control.

The desired knowledge was focused on 'knowing what' and sometimes on 'knowing why'. Knowledge was also experienced as a powerful instrument needed for increasing independence and was a central feature of the experiences. It was also experienced as irrelevant and/or false and was then ignored. Difficulty in knowing who, e.g. on the Internet, had produced the information and whether it was trustworthy was also experienced as problematic.

P6: Take cornflakes for example, then some people say that it's all right to eat them, but then you talk to another person who says that they quickly turn to sugar and that you can't eat them.

The informants experienced the need for knowledge about facts when evaluating different sources of information. Appreciated sources of information were material from the healthcare service, the Internet, television and tables of nutritional contents. Advice and information from others, e.g. friends and family, were less likely to be used.

P4: In the table of nutritional contents, I mostly look at fat levels, not so much at the carbohydrates. I think it's a bit difficult to decide if it's rich in carbohydrates...If there's lots of sugar in it... see, I haven't really grasped that yet. Now I check a little, mostly the fat levels, the amount of fat.

When they experienced a lack of knowledge, the informants had to prioritize what to focus on. Questions asked by the informants or by others uncovered a knowledge gap and started a process of searching for knowledge.

P13: You certainly have a lot of questions going round in your head. What happens if I want to have children later on, what happens if I want to travel, how does it affect my training...What happens if you get a stomach disorder... and then I start doing a bit of surfing on the Internet, and I read, and then I often write down questions as they come up. You search for quite a lot of knowledge like that.

New questions arose in different situations both before and after different experiences in daily life situations.

Experience and reflection: a source of learning

New knowledge and answers to one's questions were gained from experience along with reflection. The informants planned to gain experience by consciously trying something new (food, insulin doses, activity, alcohol) or doing something in a different way, which was compared with earlier habits. Experience was also a result of unplanned activities, when routines and ordinary behaviour could not be carried out as previously.

Along with reflection, informants used different sources of information. Earlier experience guided new decision making. Reflection could be concerned with experience from concrete situations but also thoughts about new circumstances in life and within oneself.

Surprising glucose levels or bodily symptoms were reasons to start reflecting.

P10: Yes, we were in the car and I'd had very little for breakfast and then I had three sandwiches in the car... and when we got there... I was 18 [mmol/l]...but for heaven's sake, how can it be so high when I've just been sitting still, but I mean I can't keep moving around all the time...but then I realised that ahhh, it was the sandwiches in the car, it was sort of straight up...I mean it isn't good but anyway...and that's when you learn.

Self-experience was in focus for the learning development where informants' bodies and actions were the focus of interest.

Search for knowledge connected with different feelings

Feelings were involved in the learning process. Receiving the diagnosis was in itself connected with different feelings. The changes, i.e., new conditions combined with unknown situations, were also connected with feelings. Uncertainty was common, e.g. about what to eat

and how to deal with insulin dosage, and how the glucose was influenced by different actions or situations. Experiences of being at the beginning of something, not having enough knowledge and experience, also created feelings of uncertainty.

P10: You feel a little like ahh am I too high now [glucose level] should I take more [insulin] or not, than I have to think yes I do that or no I don't so it takes a while to learn to know oneself how I react so to say.

The feeling that it was 'fun to learn' and 'exciting' was also expressed. New knowledge about greater risk of complications led to difficult feelings that needed to be dealt with, e.g. by gaining more information and thinking of how one could influence the situation.

The healthcare service as a necessary partner

In the changed conditions of the informants' lives, the healthcare service was experienced as a rock to lean on, reliable and safe to turn to in case of uncertainty. However, this assumed that the healthcare staff were accessible as well as receptive and focused on the acute, specific needs of each individual.

Health care does not meet the individual's expectations

When meeting health care staff, informants experienced that there was time only for concrete issues such as doses and glucose levels rather than their concerns and questions, which created disappointments. Feelings were the same when they met staff that gave advice that felt incorrect. Negative feelings also arose when staff gave the informants the responsibility for tasks that they had not chosen themselves, e.g. made them feel that they were responsible for

coordinating their own care when different units within the healthcare system were involved. Meeting staff that were not qualified in the field of diabetes was also experienced as negative.

P12: Then a completely new one that I've never met before, a district nurse, says ...It's very important that you look after your feet now. Yes I know, I said. Because you know that in the worse scenario they have to amputate. Surely that's painting the situation worse than it actually is, I thought.

Receiving advice that did not feel appropriate for the individual created mistrust for the health care.

Health care as the secure base to return to

Healthcare staff was also experienced as providing reliable information. Their advice was regarded as more reliable than that of others, such as family, relatives and friends. If the informants needed explanations or wanted advice on how to act in different situations, e.g. if the glucose level rose in a certain situation, the healthcare service was contacted. The informants also experienced new situations for which they wanted confirmation that they had thought and acted correctly.

P4: I called [the diabetic nurse] once when I got like a bit of a high fever. The children weren't well, they had a tummy bug. Then I got a bit of a high fever and then like I was a bit uncertain what I should do.

When uncertainty arose, e.g. when they did not know if they had taken the right amount of insulin if they had forgotten an injection or if they were sick, the informants turned to the healthcare service.

Discussion

Methodology

This study is the first part of a longitudinal study in which the same informants have also been interviewed one and three years after the DM diagnosis. The overall aim is to follow the learning process over time through the informants' experiences. In this study the early experiences are in focus because of the importance of better understanding the characteristics of learning with short experiences of illness. To understand as many aspects as possible of the learning from a daily life perspective, it was considered adequate to have a selective sampling approach. The informants included were in different age groups, working conditions and social contexts, which provided experiences with different life situations. The type of DM was not taken into consideration as the focus was learning to live with an illness with abnormal glucose level.

Learning is often a by-product of another activity and happens spontaneously and often unconsciously for the person (Kolb 1984). Therefore, we considered it appropriate to ask about situations that the informants had experienced in connection with having diabetes and not directly about the learning process as such.

Limitations of the study

A limitation in the study that should be considered in the conclusions drawn is that all the included informants were recruited from a hospital setting. This could imply that the

selected sample might have had more serious symptoms, which might have influenced their experiences and learning needs. The results might have been different if persons diagnosed without having symptoms, e.g. in a routine health check-up, were included

Issues related to the findings

The focus of the findings will be discussed with respect to aspects of knowledge and learning process concerning the participants' experience of the self and the body (cognitive and embodied), feelings (emotional) and actions (skills).

Regarding cognitive development, the informants with up to about two months' experience of DM focused on how to come to terms with and understand their new condition and the new capacity of the self and the body. The new experience in connection with the illness was a reason to start learning about the body and the self. It also became legitimate to prioritize oneself and start to listen to how one actually feels.

From the experiences it is obvious that the body had become a visible partner that also puts demands on the person. As (Price 1993) established, it is through the body the disease becomes noticeable. Knowing the body involve listening to the body and monitoring it as well as paying close attention to recognize unique patterns in it, which was apparent in the informants' experiences.

The bodily signs and signals observed by the informants in this study became a tool for understanding both the illness and the body. The embodied aspect, which means recognizing signs, reflecting on signals, trying to understand what is happening and allowing these new experiences, helped the informants to consider actions, which also involved an emotional dimension (Meareau-Ponty 2002).

Uncertainty is a feeling that was continually present in the experiences of the informants, about the self, the body, the illness and the treatment and unfamiliar situations.

Interestingly, the experienced uncertainty created motivation to be more knowledgeable in order to be certain and feel more comfortable. Other studies have also shown that people with diabetes commonly experience that they have adequate knowledge but lack of motivation to manage their diabetes (Sparud Lundin et al. 2007). In the present study when the informants had experienced diabetes for only a short time, the situation seemed to be the other way around. The diagnosis itself was a wake-up call that made it easier to deal with unhealthy behaviours even if the informants not had come to terms with the life situation as a whole. However, it might be easier for individuals to learn and change behaviour when immediate consequences are noticeable (Sundel and Sundel 2008).

Studies have also shown that the diagnosis of a chronic illness may involve both grief for a former self and a struggle to understand and accept the new self, but it is also seen as an opportunity for meaningful changes which have been needed for a long time (Bramley and Eatough 2005, Bury. 1982). Needed and meaningful changes were experienced by the informants in this study, who gave examples of such new habits. This is further discussed by (Hörnsten et al. 2004), who found that the process of changing habits was demanding, but the ability to experience the diabetes diagnosis as a starting point for a new, healthier life was described as an advantage.

The action part of the learning process was shown as creating routines that were experienced as important; routines created a feeling of being certain but were also recognized as a source of vulnerability when something unexpected happened and routines could not be followed. This is further described by (Tenulf Nylin et al. 1987), who have shown that newly diagnosed informants called for information and structured routines to follow faithfully.

Self-monitoring of glucose provided by the glucose meter enhanced the ability to associate change, e.g. in glucose levels, with change in diet or activity patterns, which (Cox et al. 1994) have also found. The glucose meter was an important tool for understanding the

body, providing proof that the interpretation of body symptoms was correct. The informants in the present study exposed themselves consciously and unconsciously to different situations to either maintain their earlier life or achieve new experiences in learning how to live with the illness. However, the informants were interested not in the advice and experience of others in their close surrounding but, rather, in seeking and exploring new knowledge by themselves, all in order to be able to deal with their new circumstances and demands in a life with the new conditions. These findings differ from those of other studies, where learning from the experience of others has been appreciated (Sparud Lundin 2008, Thors Adolfsson et al. 2008). However, the duration of the disease is one aspect that differs between the studies, which might explain the differences.

Furthermore, when the informants were meeting healthcare staff, the importance of sensitivity to the person's information and accessibility needs was experienced. Healthcare staff were then appreciated and were the key players with whom the informants chose to interact in this early stage of life with diabetes. When the patient-centred approach failed, on the other hand, this created disappointments. (Wikblad 1991) and (Tang et al. 2006) also concluded that patients want to be listened to, to be given opportunities to explain their problems and to receive information that is relevant in their daily life. Other studies have shown similar problems, e.g. not enough time to allow patients to raise questions and matters that concern them (Thors Adolfsson et al. 2004, Thors Adolfsson et al. 2008)..

Conclusion

People who have had DM for a short time gain knowledge through personal resources such as lived experience and self-reflection. The learning process includes an inner dialogue between the self, the body and the life. The learning process is concerned with grasping a new reality, and understanding a different self and body where lifestyle changes and uncertainty are

present. In this early stage of the illness the bodily signs and signals are central in the endeavour of being in control and safe. Healthcare staff should grasp the opportunity to provide the newly diagnosed individuals with the knowledge and skills required but also be aware that sharing experience with others is not of interest. When healthcare is accessible and sensitive to a person's needs, those with short-term experience of DM choose the staff as key players in the early stages of their life with diabetes.

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Conflict of interest

No conflict of interest for this study.

Author contributions

ÅK and BK were responsible for the study conception and design. ÅK performed the data collection, data analysis and was responsible for drafting of the manuscript. ÅK, BK and IK made critical revisions to the paper. IF supervised the study.

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