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A lifeworld phenomenological study of the experience of falling ill with diabetes

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Abstract

Background and aim: The aim of the study was to develop knowledge from a patient perspective about falling ill with diabetes. The focus on the process of falling ill process is useful to increase the understanding of this patient group and thus these patients could be met in a way that better lessens their suffering and better facilitates their adaptation to the illness and the new life situation.

Design: The study has been carried out within caring science and a lifeworld phenomenological approach. The data were composed by written narratives, which were analyzed for meaning.

Participants and setting: Seven persons with newly discovered diabetes at two hospitals in the south of Sweden have participated in the study.

Results: The result shows that the essential meaning of falling ill with diabetes is a fight not to become one's illness, that everything is to remain as usual and that the new situation will become the natural one. To fall ill with diabetes means to be involved in a course of events charged with emotional diversity. An initial feeling of bodily imbalance can be denied or given a natural explanation, but gives rise to a suspicion that something is wrong. When the bodily imbalance is verified as diabetes, it can be acknowledged and eventually accepted, but the acceptance is possibly an illusory or false reconciliation to be able to go on. There is anyway no choice, if they want to feel well they have to be "adaptable" to their illness, which makes demands that have to be reconciled; demands that must not be allowed to "govern" their lives. Despite being diagnosed with diabetes they still want to continue the same life and be the same persons as before—although they now carry a disease.

Conclusion: The result of the study indicates that more caring focus needs to be directed to the process of falling ill. More efforts are needed to prevent the ill persons from becoming their illness.

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Keywords: Diabetes; Phenomenology; Chronic disease; Lifeworld; Patient's experience; Nursing; lifestyle

What is already known about the topic?

- There is a substantial amount of knowledge on the disease and its treatment.
- Although nursing studies have described how the patients experience their life with the disease, no studies were found about the experience of falling ill.
- Experiences made from treating these patients show that they have difficulties in changing their lifestyle in a way

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that would lower the risk for the complications associated with the disease.

What this paper adds

- The paper describes how people diagnosed with diabetes struggle to prevent their illness overwhelming their life and previous sense of identity.

1. Introduction

In Sweden about 4% fall ill with diabetes mellitus. Of these about 85–90% have type 2, which is most often not managed with insulin, and 10–15% type 1, which is an insulin dependent diabetes, according to *National Guidelines for Care and Treatment of Diabetes Mellitus* (1999). Today's knowledge of diabetes illness is extensive, according to *Söderberg and Karlsson* (2002). Through medical advances people with diabetes have been given better possibilities to actively care for and manage their condition. In spite of this it is known that people with diabetes have difficulties in carrying out necessary life-style changes and following treatment recommendations. The difference between how one ought to live and how one lives seems to be too big to overcome. With that background we became interested in the experiences of falling ill with diabetes.

A literature search was carried out with no result concerning the knowledge of the experience of falling ill with diabetes. *Kralik et al.* (2001) explicitly say that the area is relatively unexplored. The studies that were found describe the experience of being a person living with diabetes (*Hernandez, 1995; Ternuf-Nyhlin et al., 1987*). Other studies of the area describe the care and the importance of a global approach (*Romeo, 2000*) and the importance of participation and respect for the understanding and knowledge of the person with diabetes (*Thorne et al., 1999*). The importance of knowledge, ability and a wish on the part of the patient to make necessary changes is also described (*Hörnsten et al., 2002*). *Hunt et al.* (1998) describe that caregivers and patients have different goals and different criteria for reaching the goal of the treatment of the disease, but share a common standpoint that the illness can be controlled even if it cannot be cured. Previous research outcomes (*Romeo, 2000; Hernandez, 1995; Ternuf-Nyhlin et al., 1987; Thorne et al., 1999; Hunt et al., 1998*) place further focus upon the importance of the caregiver being attentive to the needs and wishes of the ill persons.

None of the articles deal with the lived experience of the process of falling ill related to diabetes, which we found important to illuminate. The aim of this study was to develop knowledge of what it is like to fall ill with diabetes by highlighting these persons' experiences. The study should be seen as a complement to the bio-medical knowledge and other experimental studies of the illness, with a goal of

increasing caregivers' possibilities of meeting their patients' experiences, supporting them and their well-being in the changing life situation.

2. The study and its method

The phenomenon of this study, the experience of falling ill with diabetes, is explored and illuminated by the reflective lifeworld research approach (RLR), based on phenomenological epistemology as described by *Dahlberg et al.* (2008). The RLR approach is building on an interest in the lifeworld, which forms the foundation of understanding humans, our lives, health, suffering, and well-being. Researching openness is emphasized in terms of the "bridling" of the researcher's emerging understanding of the phenomenon (*Dahlberg, 2006*). The RLR approach thus opens up a research attitude to the world as it presents itself; it maintains a sensitivity to the ambiguity of the lifeworld (*Dahlberg and Dahlberg, 2003*). Adopting this approach we had the ambition to make ourselves available and sensitive to the studied phenomenon, in order to explore it as lived, in this case from the perspective of the persons' with diabetes.

To "bridle" the process of understanding does not mean a belief of setting aside all pre-understanding, which firstly is impossible. Pre-understanding is a necessary condition for understanding, but if it works "uncontrolled" it makes us see what we expect to see and have always seen. The idea of "bridling" demands from researchers a reflective and critical attitude in which one "slows down" the process of understanding in order to see the phenomenon in a new way. In the present study, the "bridling" was practised in an individual way, but we also put on effort into discussing the emerging understanding with each other, when we went back and forth between the narratives and the meanings that we thought we saw.

2.1. Participants

Ten persons who were ill with insulin-treated diabetes since 4–12 months were asked to write a narrative about the process of falling ill. The selection criteria were founded on the idea that the persons would have dealt with the initial experiences of having acquired diabetes. Persons with diabetes treated with insulin were chosen because their change of lifestyle situation is generally understood to be hard. The informants were recruited during 13 months from two medical clinics in the south of Sweden by four diabetes nurses at respective clinics, who informed them of the aim of the study. After consent from the informants their names and telephone numbers were given to the first author, who contacted the informants and informed them about the study by phone and by mail. No informants were known to the researchers before the study.

2.2. Narratives

In order to obtain expressions of persons' lived experiences, narratives were used (van Manen, 1990; Dahlberg et al., 2008). van Manen argues that writing in particular releases the lived experience. The persons were asked to write a detailed and rich narrative about their experience of falling ill with diabetes. They were urged not to leave out any thought or feeling related to their experience of falling ill and they were given instructions that it was more important to write freely from their hearts than linguistically correct.

Of the ten who were asked to write a narrative about the falling-ill process seven sent in their narratives, four men and three women. Four of the participants sent back the material with a written narrative within a month. When the other informants were contacted they replied that they were positive towards participating, but the narratives were still not returned within the promised time. One participant said that she had written the narrative and put it aside because she thought it was "silly". After being told that nothing was unimportant a very rich narrative was returned. When seven narratives had been received the research material was judged to be comprehensive and rich enough to start the work of analysing it.

2.3. Ethical consideration

All ethical considerations required in Sweden were met. The application to carry out the study was made to the operative managers at the units concerned. The informants were informed of the aim of the study, that the participation was voluntary and could be terminated if they so wished and without explanation. Written consent was given by all participants. Respect for and attention to a possible influence on the informant's health was observed, bearing in mind that the writing could evoke strong feelings.

2.4. Analysis

The process of analysis was directed towards discovering shades of qualitative meanings that emerged from the written narratives and was characterized by an intensive dialogue with the text. An understanding of the phenomenon was sought where the whole was understood in terms of details, as well as details in terms of the whole. Such analysis goes beyond given conditions and avoids linear or causal explanations and instead allows for the varied meaning of the phenomenon to emerge. The aim of the analysis was to see a pattern of meanings and, finally, the phenomenon's general structure. The concrete and lived experience that was expressed in the narratives was thereby transformed into a professional and scientific description of falling ill with diabetes.

First we present the essential meaning of the phenomenon, i.e. the characteristics of the phenomenon without which it would not be that phenomenon. Also, the essential

meaning binds the constituents together, and is the background against which the constituents "stand out" as figures. The meaning of the phenomenon is further illustrated with descriptions in six constituents: the body in imbalance, the attention of those around them, to become a person with diabetes, a changed life situation, the fight not to become one's illness, sole responsibility. The meanings within the constituents are exemplified by excerpts from the narratives.

3. Results

To fall ill with diabetes means to abruptly become another person, one with diabetes. As such one becomes involved in a course of events marked by emotional diversity. An initial feeling of bodily imbalance can be (partially) denied or given a natural explanation. If it persists, the feeling gives rise to a suspicion that something is wrong. When the bodily imbalance is verified as an illness the ill person is thrown between feelings that the situation is inexplicable, unreal, incomprehensible, and on the other hand feelings of relief, which are caused by the bodily imbalance receiving an explanation. The strain of all those contradictory feelings and the bodily imbalance can be hard to embrace and lead to existential chaos and confusion, which means suffering as well as a push towards an understanding of the situation and its gravity.

When the diabetes illness becomes a fact, it can rather soon be acknowledged and eventually accepted. However, the acceptance is possibly an illusory or false reconciliation to be able to go on. There is anyway no choice, if they want to feel well they have to be "adaptable" to their illness, which makes demands that have to be reconciled; demands that must not be allowed to "govern" their lives. *They do not want to become their illness*. Even if they are ill with diabetes they want to continue the same life and be the same persons as before—although they now carry a disease. At the same time a feeling of loss of one's earlier life can manifest itself.

3.1. The body in imbalance receives attention of others

The informants described how they were plagued by a strong thirst and large amounts of urine, tiredness and a loss of weight. They tried to explain the troubles as a natural cause, e.g. hard work, summer heat and bodily exertions. One informant related: "*When I fell ill I thought that I had come down with stomach influenza*" (B:2).

The bodily imbalance is thus given an explanation, i.e. a normal feeling of being unwell which is part of life. To want to feel well and not be ill may produce these natural explanations. One informant wrote: "*The occupational health nurse began by asking if I felt well and I naturally answered yes, because I wanted to feel well*" (B:5). This can be understood as a way of holding back an unpleasant feeling, which more and more intruded, that not everything

was all right: “*So somewhere I understood that something was not right, but I did not understand what*” (B:5).

One reason why those who had fallen ill with diabetes sought another explanation than the natural for the imbalance that had arisen was that relatives noticed it and became suspicious and worried. One informant related: “*My father has diabetes and was going to check his blood sugar and then my cohab thought that I should do it, too*” (B:1).

The persons can also themselves feel that something is not right and the informants took for example, help from relatives with more knowledge to discuss and look for an explanation of the observed feeling of imbalance. Others had their illness pointed out at ordinary health controls. To some people worry and suspiciousness from persons around them could be felt as an intrusion, when they pointed out and brought out their suspicions. One informant expressed this as: “*Then I was almost angry. Did people imply that I had acquired the “disease of a fatso”? Charming, now you know who your real mates are*” (B:3).

3.2. To become a person with diabetes and encounter a changed life situation

From being well one is suddenly struck by illness, “*from one day to the next*” (B:5). When the disease is a fact and the ill person had been told of the reason for the bodily imbalance, a crisis-like experience unfolds. One informant wrote “*Everyone was shocked, my cohabiting partner and I went to the emergency ward. // I did not fully understand what had happened, but it did not feel fun*” (B:1). The insight of illness can, however, also feel good: “*It was not until then that I understood that the incredible thirst that I had suffered from all summer was due to diabetes*” (B:5). It can be a relief to get an explanation of subtle but worrying feelings of imbalance. Anyway, the diabetes illness is a fact, i.e. no delusion or something that can be changed: “*Now it was suddenly not only an expression but a bitter truth for me*” (B:5).

Being informed of the illness felt unreal and hard to understand, but by and by the realization came of what it means to have acquired diabetes. One informant wrote: “*To say the words – I have fallen ill with diabetes felt strange, but at the same time it made it a little bit more real*” (B:5). From the informants’ narratives emerged that as the disease is chronic (but not fatal), they will be forced to live with it for the rest of their lives, but that treatment is necessary and can make a good life possible: “*... if I do not take my medicine I will not survive*” (B:2).

One has to adapt to the changed situation. To have to change one’s diet can be felt as a lot of restrictions at the beginning. However, the informants said that they later on could see new possibilities to satisfy their wishes and see the advantages of a good diet, which was expressed in the following: “*You painted horror scenarios, that I would never more be allowed to eat junk food, sweets or drink lemonade, but instead only have to eat beans and broccoli. Of course it does not work that way. I can allow myself sweets sometimes,*

but in general I have stopped which is essentially good” (B:4).

Even the treatment can feel frightening at first, but when the effect of the treatment is noticeable and the body returns to be functioning again it can make up for some of the discomfort. One informant expressed it like this: “*The immediate effect after the first syringe was that I did not have to rush to a toilet when I felt the need to go, nor did I have to pee as often as before. That had been a very big problem for me that I got rid of overnight*” (B:5).

An understanding that later developed was that in the future different activities would have to be planned. It turned out to be more difficult to carry out spontaneous activities, which brought with it a lack of autonomy. One informant described this as follows: “*There are some problems with having diabetes. You have to have regular mealtimes and you cannot be sloppy about it. // So it becomes a problem when you are away at a party, when perhaps it goes a little bit longer between meals*” (B:1).

3.3. The struggle not to become one’s disease is a sole responsibility

People around, e.g. relatives and friends, can be worried and want to take care, and thus begin to behave in a different way than earlier towards the one who has become ill, which can be felt a strain. One informant described it in the following way: “*You can explain it like this that it is not the fact that I have to take shots, that is particularly hard, but that people have to treat you in a special way because you take shots that is the hardest. // That I am not a different person and that I am neither kinder nor more stupid and strange just because I fell ill*” (B:3).

Despite having fallen ill with diabetes, they did not want the disease to take the upper hand but that life would continue as before with slight modifications. There was a desire to be treated as the same person and in the same way as before. One informant wrote: “*Overnight everything changed. People stopped asking what you did at work or if you had fun when you last met your mates and instead only asked how you felt and what the blood sugar readings were*” (B:3).

To gain control over one’s illness and feel well one has to take it into consideration all the time in the beginning. If the control over the illness is neglected the risk of damage to the body later in life increases, which the informants were noticeably aware of. They lived with the responsibility for this control. It could not be switched off, which could give a feeling of solitude with the disease. One informant wrote: “*If you want to feel well, you have to manage it so that it does not damage the body, for you have to live with that for the rest of your life // but luckily you only damage yourself and no one else*” (B:1).

At the beginning it could feel difficult to prick oneself to give insulin. Pricking and syringes felt strange and frightening, but to be independent and free one had to manage one’s

own treatment. Having started with the first injection the fear disappeared and it became an everyday act.

3.4. Apparent and uncertain acceptance

The analysis points at a possibility for those who fall ill with diabetes to eventually accept their situation of being chronically ill. The informants expressed the feeling that there is nothing to be done about the situation. “*It is the way it is*” (B:2) and one can do nothing but accept it. “*If you have fallen ill with the disease, you have*” (B:2). One patient wrote: “*This is nothing I can do anything about. I just have to learn to live with the disease*” (B:1).

They just have to accept that things will never be as before. Gradually this new way of living has the potential to become natural and work well. The informants expressed a wish to downplay the attention given to the disease. One informant described it in the following way:

“That I have come down with diabetes is something I actually do not think of very much and I do not like talking about it either. I can compare it to having a weird neighbour. You cannot get rid of him and you do not want to talk to or about him, so you just have to relax and go on living” (B:3).

The informants expressed that they accepted the situation but also a certain measure of sorrow over the loss of life that should have been and the loss of spontaneity. To accept the situation thoughts turned to the fact that there were others who had it worse. One informant wrote:

“It is true it was tough for a while, but what was one to do, there are those who experience worse. //The syringes work well. // Today I do not worry especially over my illness, it sort of just is there” (B:4).

4. Discussion

In the present study people who have fallen ill with diabetes have been given the opportunity to put their feelings and thoughts into their own words. Initially it was difficult to collect the study material. At the introductory telephone contact they were in favour of taking part, but the narratives were slow in coming but when they were sent they contained rich information.

On reading the narratives of the informants it was surprising how they had tried to give natural explanations for their signs of bodily imbalance. The wish for a natural explanation of the imbalance they experienced was very strongly felt. The signs could be strong and crippling. Still they did not want to see them or admit that they existed. If someone in their surroundings asked about the disease, the ill person could deny it or get angry, even if the signs of imbalance were obvious. When then the disease became a fact, there was an upsetting period of time with a lot of emotions, but the disease was accepted fairly quickly, which has also been noted by Richardsson et al. (2001). The result

of the present study indicates that the persons who have fallen ill with diabetes outwardly accept their new life conditions for everything to quieten down and appear to be as usual again. There is a wish for the disease not to take up such a large part of their lives and they do not want to become their illness. The results of the study can be compared with William-Olsson’s text (1989), where she writes: “In their illness people with diabetes are both ill and well, which makes them want to hide their illness in order to be accepted on healthy people’s terms and not be questioned” (p. 7). To be named a diabetic means to some that they are handicapped and weak even if they feel healthy and strong. This can explain why some patients do not want to participate in or be an active member of the Diabetes Association¹ and that they do not want to sit outside the door of the diabetes ward and show their handicap. Patients who have taken part in medicine studies with a structured treatment programme have related how they wait for it to end and that everything “returns to normal again”. The illness must not become a large part of their lives. Above all it must not “become life”.

The unwillingness or struggle not to capitulate is expressed in quotes from other studies. Hernandez (1995) describes it as follows:

“I do not like the question: Do you have a good control? That sounds as if the diabetes illness controls my life.” Everyone tries to control me. // It is not control I strive for but to live or bring together the diabetes illness and life in a good way” (pp. 34–35).

In another study (Kralik et al., 2004) of persons’ with arthritis self-care, the struggle is described in the following way: “*Jan’s advice was, do not let the arthritis dominate your life, but try to incorporate it into your life*” (p. 264). The quotes show that it is not only the results from the present study that give evidence of unwillingness and struggle not to become one’s illness. This struggle is shared by other persons with diabetes and also persons with other chronic diseases.

Perhaps the struggle not to become one’s illness and instead keeping everything as usual can illuminate what some researchers call “lack of compliance” (Hunt et al., 1998; Paterson et al., 1998; Ternuf-Nyhlin, 1990; McCord and Brandenburg, 1995). Romeo (2000) describes the problem as health care and the ill person having different goals with the treatment. Furthermore Hörnsten (2004b) describes the difference in the understanding of the disease and the view of care between patients and nurses in the diabetes care. The findings illuminate how nurses consider their professional knowledge higher than that of their patients and are given a bad conscience by some decisions taken by their patients, for example when they cannot convince them to take a greater responsibility for their self-care or stop

¹ Swedish Diabetes Association.

smoking. According to Hunt et al. (1998) the goal of the caregivers is a good control to minimize the risk of developing complications, while the goal of the ill person first and foremost is that life with the disease should function. Hörnsten et al. (2004a) describe the difference between getting the diagnose type 2 diabetes and incorporating the disease into one's daily life.

The present study shows how the existential needs are intertwined with the biological ones. The seven informants with short experience of the disease describe their awareness that “if you want to feel well you must look after it”, but also the difficulties of handling the disease in a good way at various social functions, when others set the program. The treatment demands regularity concerning food and taking medicine. The informants describe how they can forget the time, when they are engaged in different tasks. If they forget to eat or do not eat enough the blood sugar becomes too low, which makes them feel ill and risk losing control, or even lose consciousness. Patients do not always know why their blood sugar level falls or rises. They have eaten and drunk as usual in relation to the activities they have performed, but other factors, for example hormonal, have influenced the blood sugar. The difficulty of having control of the blood sugar level is described by Ellison and Rayman (1998). Those who in the study were called experts at self-care experienced that they sometimes managed the control to 100% while at other times only to 40%, which testifies to the difficulty of controlling the blood sugar level. The study also shows that a well-balanced blood sugar is required for a person to feel well. Ternulf-Nyhlin (1991, p. 197) describes it as “walking a fine line” between maintaining good control and losing it. An uncontrolled blood sugar level can many times lead to anxiety. The ill ones are aware of the gravity but do not always understand the full situation. They need to realize that it can be circumstances over which they simply have no control, and that a high blood sugar level does not necessarily mean that they neglect their treatment (Ternulf-Nyhlin, 1990). Knowledge about the difficulties of attaining a well-balanced blood sugar level puts them in need of knowledge and support from the caregivers.

The result of the present study gives rise to a suspicion that there is only a seeming or false acceptance of the new life situation including the disease. This suspicion is partly shared by William-Olsson (1989, p. 64), which she expresses with the words “Accept your illness – more easily said than done”. If the acceptance is illusory one can ask oneself what it can mean for the ill persons? Do they accept the new situation only to escape thinking about the disease, get on with life and manage the demands that are made? Is it as Hunt et al. (1998) describe that they strive towards “taking care of self” to lessen the influence of the disease on their lives and social functions. Does it lead to a life-long suffering? If it does, what can we do to help these persons to decrease their suffering and more openly come to terms with their new situation?

The need to answer the question of how we can help persons with diabetes to lessen the suffering and increase

well-being grows stronger and stronger. These patients must be involved in their care and their own health processes, and be met with trust and respect. Paterson (2001) (p. 580) describes in his study how the caregivers invited participation in questions concerning treatment by inquiring about the patients' experiences. The patients felt, however, that their experiences and knowledge was of no importance when the continued treatment was prescribed. For those patients who took a great personal responsibility for their treatment this was felt frustrating, while those who did not wish to take personal responsibility were satisfied. The informants in the present study have expressed that it felt good when the caregivers made them involved, when they listen to their narratives and on their own tell the patients why and what care measures they are taking. To invite the patients' life-world into the care cannot be wrong.

5. Conclusions and implications

The result of the study indicates the necessity of a lifeworld perspective in care. Lifeworld sensitive care can support the persons who fall ill with diabetes to gradually incorporate the illness into their life situation, which may lessen their sorrow and suffering. Such care can prevent the illness from taking over and dominating existence and the everyday activities and may help people who fall ill with diabetes to reconcile themselves with their new life situation, finding solutions that make it possible to continue leading a rich life with their illness as an unwanted but persistent companion.

Conflicts of interest

None.

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