Encumbered by vulnerability and temporality – the meanings of trigger situations when learning to live with diabetes

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ABSTRACT

The aim of the study was to illuminate the meanings of trigger situations in learning to live with diabetes. Thirteen participants, with either type I or type II diabetes, were interviewed on three different occasions over a three year period after being diagnosed with diabetes. A phenomenological hermeneutical method for interpreting the interview text was used for analyzing data.

When learning to live with diabetes, the meanings of trigger situations were described in the overall theme; 'encumbered by vulnerability and temporality' and four themes; 'unsustainable situations', 'an unpredictable body and life', 'dependent on oneself and others' and 'the unforeseeable demands of the future'. The unsustainable situation arose where one was forced to choose between incompatible needs and circumstances over which one had no control. One's earlier understands of a body that had become unpredictable had to be challenged, demanding a changed understanding of the future and one's own vulnerability. At the same time trigger situations presented an opportunity to learn, requiring a need to understand involving reflection, unanswered questions and new insight. If health care personnel can identify these worries and questions, knowledge gaps can be identified and reflected on in order to stimulate learning.

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-the meanings of trigger situations when learning to live with diabetes

BACKGROUND

Living with a chronic illness has been described as needing to understand what had earlier been taken for granted (Asbring 2000, Charmaz 1983), illuminating an interlacement between living with chronic illness and learning in everyday life. Common challenges and learning needs across different chronic illnesses have been addressed e.g. in relation to recognizing symptoms, taking appropriate action, decision-making, lifestyle management, adherence to medication and going for medical check-ups (Rankin & Stallings 1996, Thorne et al. 2003). More specific to diabetes learning needs in relation to dietary adjustments, regular exercise, glucose testing and decision-making concerning blood glucose levels and medical treatment have been addressed (ADA 2012, Hörnsten 2004). According to Meleis et al. (2000) living with chronic illness involves learning needs in relation to knowledge, skills, values, role modification and identity redefinition. Coming to terms with new demands related to the illness has been described as important for managing a changed life, feeling mastery and control, also described as a healthy transition (Meleis et al. 2000). Others have described well-being, illness integration and a balance in everyday life (Kralik et al. 2004, Kralik et al. 2006, Whittemore et al. 2002) and independence from health care (Govan et al. 2011, Hernandez 1995, Price 1993) as outcomes relating to a healthy transition.

It is essential to be active and engaged to manage a changed life situation and to experience health despite illness (Whittemore & Dixon 2008, Meleis et al. 2000). Riegel et al. (2012) found that being actively reflective was associated with a consciousness in relation to self-care decisions and the ability to manage everyday demands in caring for oneself when living

with diabetes. Vég (2006) found that those who were active in the daily management of their diabetes had better metabolic control than those who were more passive.

Adults are found to be active and engaged in learning when facing problematic situations, triggering a need to understand (Jarvis et al. 2003). This is further described as a situation highlighting the discrepancy between earlier experiences and new experience as well as being a situation one has no preset responses to, which might result in reconsidering a way of thinking or one's actions (Jarvis 1987a, Jarvis 1987b). A situation creating tension between an earlier way of managing a situating and new demands can change a latent learner into an active learner, being a catalyst for experiencing a readiness to consider or make changes (Jarvis 1992, Knowles 1975, Kungu & Machtmes 2009). Triggers can be chosen consciously in order to stimulate learning, e.g. as a starting point for a case in problem-based-learning presented as a text or a picture (Azer 2007), or an unexpected phenomenon raised in unfamiliar situations in everyday life (Lyon 2002). However, a trigger situation is not per se interlaced with learning, as 'non-learning' is a common response to situations even when the need for learning is experienced (Jarvis et al. 2003).

According to Lohman (2003) understanding what is experienced as triggering when not being able to respond in an adequate manner in different settings is important for understanding learning. Kungu and Machtmes (2009) argue that understanding triggers for learning is to better understand how people participate in their own lifelong learning. However, trigger situations are an unexamined area and to the best of our knowledge research focusing on trigger situations in relation to diabetes has only been sparsely conducted. One exception is Price (1993) exploring 'problematic situations' to describe a model for learning diabetes self-management. Hörnsten et al. (2011) and Jutterström.et al. (2012) have raised turning points as specific events or situations important in coming to terms with self-management. A deeper understanding of trigger situations could provide an insight for reconsidering approaches and

designs of patient education. The aim of the present study, therefore, was to illuminate the meanings of trigger situations in learning to live with diabetes.

RESEARCH DESIGN AND METHOD

A phenomenological hermeneutical method, inspired by the philosophy of Paul Ricoeur (1976) and developed by Lindseth and Norberg (2004), was used for interpreting transcripts of the interviews with persons living with diabetes. The method consists of three stages; naïve understanding, structural analysis and a comprehensive understanding. However, there is a dialectal movement between the parts of the text and the whole (Lindseth & Norberg 2004). This is described as the hermeneutic arc and according to Amdal (2001) Ricoeur's hermeneutic arc combines a movement from existential understanding to explanation and from explanation to existential understanding.

Participants and setting

In the present study thirteen participants, 4 women and 9 men, with different living conditions (3 living alone, 10 living with partner) and working conditions (11 working, 2 not working) and types of diabetes (5 with type 1 and 8 with type 2) as well as a variation in ages between 26 and 65 (median 43) years, were included. The participants were recruited from an endocrinological ward at a Swedish metropolitan university hospital. On inclusion all participants were newly diagnosed with diabetes and Swedish-speaking. Potential participants were informed about the study by mail approximately one week after being discharged from hospital where they had been treated for newly diagnosed diabetes. A few days later, they were telephoned by the first author (ÅK) and could ask questions before deciding whether to participate or not.

Data collection and analysis

Participants were interviewed on three different occasions after being diagnosed with diabetes; between the first and second month, after one year and after three years. As all participants (n=13) agreed to be interviewed at all three time-points, the analysis totally 39 interviews. All interviews comprised the same interview questions. The initial question was 'How do you experience living with diabetes?' Later on the participants were asked to narrate situations where they had had to take their diabetes into account. Participants were encouraged to narrate as freely as possible of their experiences. Interviews were conducted at the hospital, at the place of work or in participants' homes, according to participants' preferences, and lasted between 45 and 70 minutes. All interviews were audio taped and transcribed verbatim. The interviews were read through in order to identify situations in the texts involving a trigger, e.g. narrative with words such as; "feels uncomfortable, can't manage this, don't know how to cope, or this bothers me".

When the trigger situations were identified (n=59), they were sifted out from the rest of the text to be analyzed. The comprehensiveness of the transcribed text for each situation varied between one and two and a half A4 pages each. If the same situation was narrated on different interview occasions by the same participant the texts from the different occasions were brought together as one situation. A naïve understanding aiming to grasp the meaning of the text as a whole was formulated in an ongoing process after reading the identified text several times. The identified text was then divided into meaning units, consisting of parts of the text referring to the same meaning. The meaning units were condensed and abstracted and read through and reflected upon in relation to meanings; see Table I for the analytic stages. In an ongoing process, subthemes and theme were formulated and these are presented in Table II. The naïve understanding was then modified in relation to the structural analysis by moving between the two, as a form of validation. Lastly a comprehensive understanding was

formulated. The naïve understanding, the subthemes and theme together with the authors' interpretation, including our pre-understanding and relevant literature, enabled a deepened understanding of the phenomenon as a whole (Lindseth &Norberg 2004). According to Ricouer (1976) it is the relationship between being familiar and keeping at a distance from the text that allows new meanings to become visible. Familiarity with the text is in the naïve understanding and the comprehensive understanding, while a distance from the text is maintained in the structural analysis.

Table I: The analytical steps in the structural analysis

Table II: Main theme and themes

Ethical considerations

This study was performed in line with the Helsinki Declaration (1996) and the project was approved by the Regional Ethics Committee (Dnr 03-589 2010/640-32). Before each new interview, participants received both written and oral information about the study and gave their verbal informed consent. The participants were guaranteed confidentiality and interview tapes and details of the participants were stored in a secure cabinet. The participants were reassured that their participation was voluntary and that they could withdraw from the study at any time.

FINDINGS

The findings report the naïve understanding of trigger situations when living with diabetes and present a structural analysis with one overall theme and four themes.

Naïve understanding

Troublesome emotions were central in the trigger situations. To be insecure when the body was different from before involving insecurity that hampered daily life. Dissatisfaction and frustration were salient as the body had to be recognized but the body reactions were hard to understand. Realizing that the body was vulnerable and its reactions unpredictable and illogical raised the need to understand. In the trigger situations awareness of unspoken demands and expectations arose. There was a need to act when changed circumstances appeared, and at the same time acting and making decisions was hard when one was not sure of the alternatives or the consequences of the choices made. Significant others became important in the trigger situations and one was dependent on others to achieve well-being. Yet, depending on others in certain situations was stressful involving insecurity regarding both one's own and other's capacity. To re-experience earlier situations and knowledge was important in the situation. New questions and learning needs arose and there was concern about probable or expected situations in the future.

Structural analysis

From the analysis there emerged one overall theme, 'encumbered by vulnerability and temporality' and four themes; 'unsustainable situations', 'an unpredictable body and life', 'dependability on oneself and others' and 'the unforeseeable demands of the future', which illuminated the meanings of trigger situations in learning to live with diabetes.

Encumbered by vulnerability and temporality

Life and own vulnerability emerged in the trigger situations as an unsustainable situation with needs that could not be reconciled. Vulnerability was to be dependent on others as well as oneself with insufficiency being apparent. Temporality was merged with the insecurity of the future that would present unforeseeable needs. Temporality was also that one was different from before, as life and one's body were now unpredictable and hard to understand.

Unsustainable situations

Losing control and being vulnerable in a complex situation involved one's whole existence, changed one's previous understandings of living and presented an opportunity for learning. The situations were demanding since they raised an awareness of needs, expectations and demands that one had not earlier needed to consider, making it difficult to live. Being challenged with an understanding of feeling unfamiliar with oneself was frightening and tiresome.

Not understanding how to interpret or manage a complex situation involved insecurity, with a need to act. One was forced to choose between incompatible needs and circumstances over which one had no control.

When I was going to take exercise I thought it was a bit tough, because then I had to take blood glucose and then, Oh, should I or should I not exercise now, or should I eat something first, what should I do? (P13).

It was demanding not knowing what to do facing the different options or wishes, as well as doing nothing. For making choices, identifying priorities and options and understanding the consequences, reflection and information seeking were important.

An unpredictable body and life

When the body displayed unfamiliar signs or blood glucose values were unpredictably high or low insecurity arose. There was a need to focus on the body and its reactions when one was not only surprised but also did not feel well. Recalling knowledge gained in previous situations to try to understand how to avoid or manage similar situations in the future was a constant exercise. Needing new or different knowledge, or wishing one was capable of acting differently was frustrating as well as to misjudge one's body.

My feet were badly sunburnt, so I learned that the feet must be looked after, I knew I should look for wounds and stuff, but not to protect them when I was swimming, that was a big mistake, so now I have to be aware. I think I was given that information earlier but it probably went in one ear and out the other (P03).

Becoming aware of one's own vulnerability was tough emotionally and triggered a need to better protect the body to avoid feeling pain in the future, a learning experience.
Social situations were also unpredictable. Being required to manage the unfamiliar, when for different reasons the routines or habits that usually had ensured the security of one's everyday life could not be maintained, gave rise to insecurity and raised new questions.

For all those four conference days my blood glucose levels were much higher. There were irregular meals, as we met at 7.30 pm and had a drink. When is dinner I wondered, 8.30 pm or when? And all of that of course made it difficult to know when the heck I should take my insulin shot, with the snack at 5 pm? ... or at dinner?, No that would of course be too late (P12).

Situations were both familiar and unfamiliar. A similar situation could have occurred before having diabetes, but by being changed, the situation was now a trigger situation.

Dependent on oneself and others

Trigger situations raised awareness of being dependent on others for one's well-being but the collaboration with others was fragile. Situations when one's own and others' insufficiency became apparent hampered living with diabetes, but at the same time was a trigger for learning. Unable to deal with a situation by oneself the information, experience, advice and confirmation of others were needed. Decision-making was in collaboration with others. Realizing one was dependent on others for managing a life with diabetes, and at the same time facing others' lack of knowledge and prejudices, including health care not being organized to meet one's own needs, was frustrating and brought the need to find one's own solutions.

When I got this job I said, Just so you know, I have diabetes, and they had no problem with that but then it stopped at that .... the first three months, I had no lunch at all because there was a lack of staff. I had, so to speak, a working lunch .... but I got to solve it in one way or another .. I sent the terminal guys when they bought their lunch to buy for me too, but that was definitely not at the right time for me ... but then because I knew basically that it would happen again the next day I brought extra, extra sandwiches for example, to be able to keep my levels consistent, OK, but a little messy (P03).

To have to solve the situation by oneself, was an opportunity for understanding more about one's changed circumstances for living, but also to feel alone and helpless, realizing one was dependent on oneself to manage the situation.

To have changed potential to participate in different social settings was to be different. Facing circumstances over which one had no control, such as having to take into account other persons' expectations when choosing how to manage a situation, was hard. In trigger situations awareness of expectations of how to behave in a certain way became obvious. However, it was impossible to take part as expected, while other needs also had to be satisfied or one lacked information that was important to manage the situation. Social demands became visible in the situation. Incompatible needs were exemplified in wanting to participate in everyday life as one used to but at the same time having a need to feel secure, with a need to stabilize routines and habits, a contradiction.

The unforeseeable demands of the future

Just imagining a situation could be a trigger situation, needing to speculate to identify different potential obstacles and make priorities in advance. When the situation arose it was not always certain that a problem would occur. Demands in the future further pressured the situation when one addressed what had not had to be considered earlier.

We were going on a skiing holiday, a pretty active vacation I thought, but I discovered that slalom is not at all demanding for insulin regulation. No, it went just fine and I always have a small backpack with fruit, but before I went I thought, God, I might have to eat a lot of food all the time (P10).

One's own vulnerability was a trigger, raising an understanding of living in a time continuum. In situations of unsustainability, vulnerability, dependability or when the body reacted

unpredictably one questioned one's own ability to understand and manage one's own life *"but God, can I handle this by myself* "(P13) and there arose an insecurity in not knowing what to expect. Past, present and the future were to be a coherent whole. Not only what was happening here and now was important, but also situations in the future were reasons for worries and triggered reflection and planning.

COMPREHENSIVE UNDERSTANDING AND REFLECTION

When living with diabetes the meanings of trigger situations were to be challenged against the earlier understanding of oneself and the body with a changed understanding of the future. An increased understanding of one's own vulnerability meant an increased awareness of probable challenging situations in the future. The past and the future were important for understanding the situation, as the unpredictable body was remembered in the past when the body was predictable, and then compared with the present when the body was unfamiliar involving an increased awareness of what was to come. Merleau- Ponty (1945/2002) describes presence as a field with a 'double horizon', with openness both to what already has passed by but also to what may still come. The body both inhibits as well as assumes space and time. As time is subjective a changed body, inseparable for the subject and the world, means a changed time consciousness that becomes visible in these situations. In the present study decision-making was a request to choose within a limited time span. At the same time the decision was made because of its importance for the future and was based on experiences from the past. This can be understood by Merleau-Ponty (1945/2002) writing of time as 'altogether', a flow that runs from the past towards the present and the future, influencing each stage. In the present study trigger situations were an extension of the horizons as a different consciousness of one's own vulnerability and an unpredictable future.

Experiencing a trigger situation in relation to living with diabetes involved burdensome requirements together with an awareness of being changed as a person and having an unpredictable body, and unsatisfied needs and insecurity as a result of feeling unfamiliar with oneself. The unpredictable body became visible and had to be acknowledged. The physical body had to be understood cognitively as the situations made the person aware of something that earlier had been a physical process that the body performed automatically, an activity taken for granted. A trigger situation in the present study interlaced the whole person as an emotional, physical and intellectual being with limited freedom to choose. One's own vulnerability, fearing for one's own existence was a driving force for learning as there was an apparent need to manage the situation. However, learning in the present study was painful and not a voluntary activity, even with regained control and insights, being different from enjoyable learning described in other contexts (Knowles 1975). Rager (2009) describes the 'emotional hook', making the person aware of change, as the beginning of the learning process. At the same time emotions, such as fear, also hamper a learning process making the person less able to deal with, for instance, information (Rager 2003, Rager 2009).

Trigger situations when losing control were associated in the present study with frustration, but were also a driving force for learning, towards understanding more and gaining control even if it was not a self-chosen learning activity. This is further described by Paterson (2001) and Kralik (2002) as living in illness involving focusing on one's illness, which includes learning but at the same time not being able to focus on other things in life which are associated with health. At the same time others have highlighted the importance of learning to experience health despite living with a chronic illness (Whittemore &Dixon 2008). However, losing control when living with chronic illness has been associated with losses and uncertainty as well as failing to achieve satisfying metabolic control (Aujoulat et al. 2007, Jenum et al. 2008, Saydah et al. 2004). From a learning perspective trigger situations, such as experiencing

an unpredictable body with fluctuating blood glucose, were an opportunity for learning and understanding more about oneself as well as one's changed conditions for living. However, fluctuating blood glucose was in the present study associated with not feeling well, and has in other studies been associated with the risk of developing diabetes-related complications (UKPDS 1998). A trigger situation, in the present study involved experiencing pain, frustration and insecurity, but was also an opportunity to learn more and to be better prepared to deal with a life with diabetes in the future. WHO's (1948) goal for health as 'optimal well-being physically, mentally and socially' needs therefore to be reflected upon in relation to time.

Trigger situations could be something expected, such as worries for predictable situations also involving reflection and identification of potential problems. It was common that trigger situations involved emotions and questioned earlier understandings with the potential for engagement and a 'readiness' to learn (Knowles 1975). With 'interpersonal relationships' involving observation, communication and recording, nursing can be 'growth-promoting' (Peplau 1987, Peplau 1988). Focusing on trigger situations, experienced or expected, health care staff can help patients to learn from their own experiences of everyday life.

Methodological considerations

Even if learning is individual as well as contextual (Rager 2009) learning is also universal (Jarvis et al. 2003) and the findings from the present study can be considered of importance for other contexts such as common learning needs and demands among people with different chronic illnesses, which have been identified in other studies (Rankin & Stallings 1996, Thorne et al. 2003). However, a limitation in the study is the fact that all participants were recruited from the same geographical area and the same clinic and therefore diversity

concerning the health care system and specific cultural issues was lost. The main reason for not including participants based on types of diabetes, common in most diabetes studies, was the focus on learning and trigger situations when living with a changed health situation. Differences in types of diabetes as well as medical regimes in the present study were considered to give a desired variation in relation to the phenomena of interest.

The interview questions in the study were inspired by both an assumption of experiential learning (Jarvis et al. 2003) as well as the specific situations in daily life raised by Price (1993) as important for learning. However, Price (1993) uses the formulation 'problematic-situations' which was consciously not chosen in the present study, as a trigger per se does not have to be 'problematic' or experienced as negative (Azer 2007, Hoad et al. 2013) .

According to Ricoeur (1976) there are several ways to interpret a text. In the present study the analysis process and findings have been discussed in seminar groups and among researchers in order for the authors to stay open to different possible meanings of the text. However, according to Ricoeur (1976) our understanding is always based on our previous understandings. There is a dialectical movement between the need to stay close to the text and to keep a distance from the text for the authors to become aware of meanings becoming visible in front of the text. Still, interpretation of a text is always dependent on the reader and the authors' earlier knowledge and understanding can both be an advantage and disadvantage for understanding more. For the first author, with many years of experience as a nurse in diabetes care, there was a risk of being absorbed with what Merleau-Ponty (1945/2002) describes as 'the conventional understanding of the phenomena' as it is familiar. A need for the author to step back, to 'bracket' (Dahlberg et al. 2008) together with discussions with the other authors, some with less experiences of diabetes care, was therefore necessary in order to understand something in a different way than earlier. An illustration of the analytic process

and quotations in the findings section have both been included in order to increase the trustworthiness of the study (Elo et al. 2014, Morse et al. 2002) .

RELEVANCE FOR EDUCATION AND PRACTICE

To experience trigger situations in everyday life living with diabetes has in the present study been shown to give rise to strong emotions, along with feeling vulnerable to new worries for the future as well as giving rise to new unanswered questions. If health care personnel identify these worries and questions, by asking about both experienced as well as simulated situations, knowledge gaps and problems can be identified. These identified problems and needs for knowledge, based on the patient's own concerns and experiences can form a foundation for learning, as it has shown in the present study to be associated with emotions and engagement, which are essential for adult learning (Knowles 1975). By stimulating an active way of learning through reflection and discussion, health care staff can help patients to learn and understand based on situations in everyday life experiences. Such an approach is both a way of giving person-centered care, based on the patient's individual needs and problems (McCormack & MaCance 2006), as well encouraging the patient to learn and develop in order to achieve a healthy transition to living with diabetes.

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TABLES

Table I: The analytical steps in the structural analysis

Meaning unit	My son had a traffic accident and was in hospital… my blood glucose values were totally out of line, frustrating, but I didn't care everything was about taking care of him.,. He was severely injured and it was always a mess …I ignored food and injections... expended all my energy on him..
Condensed meaning unit	son in hospital , expending all my energy on him, ignoring own needs for food and medication
Abstracted meaning unit	prioritizing the needs of a severely hurt child at the expense of own needs
Theme	Unsustainable situations
Overall theme	Encumbered by vulnerability and temporality

Table II: Overall theme and themes

Overall theme	Encumbered by vulnerability and temporality
Themes	Unsustainable situations An unpredictable body and life Dependent on oneself and others The unforeseeable demands of the future