

From DEPARTMENT OF CLINICAL SCIENCES,  
DANDERYDS HOSPITAL  
Karolinska Institutet, Stockholm, Sweden

# **LEARNING TO LIVE WITH DIABETES - AS EXPERIENCING AN EXPANDING LIFE WORLD**

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**Karolinska  
Institutet**

Stockholm 2011

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ISBN 978-91-7457-218-6

Printed by



[www.reproprint.se](http://www.reproprint.se)

Gårdsvägen 4, 169 70 Solna

## ABSTRACT

*Introduction:* Chronic illness, such as diabetes, results in a transition process involving a variety of changes in both bodily function and conditions for living, and requiring broad knowledge and understanding in order to meet new demands. The outcomes of a healthy transition are described as well-being and mastery, in contrast to vulnerability and dependency. Little is known about how time for experience contributes to the transition of living with a chronic illness.

*Aim:* The overall aim of the thesis was to illuminate the transition of living with diabetes during the first three years after diagnosis, in order to reach an understanding of how better to create more person-centred care.

*Design:* The study has a life world phenomenological approach with a longitudinal, descriptive and interpretive design. Thirteen participants were interviewed within two months after diagnosis and again after three years. A selected sample approach was used. For study **I** a qualitative inductive content analysis was used and for study **II** a phenomenological-hermeneutic method.

*Findings:* In study **I** four themes were found; 'taken over by a new reality,' 'the body plays a role in life', 'different ways of learning' and 'the health care service as a necessary partner' and in study **II** one overall theme; 'Experience for understanding the individual meaning of freedom and control in living with diabetes' and two themes 'Solving the life-puzzle – a delicate balance to create the desired life' and 'The need for being in control of your own health'.

*Discussion:* For a healthy transition when living with diabetes, the ability to interact with others in order to share their experiences was crucial and contributed towards participants understanding themselves and their life world. In order to be able to interact, participants had to understand their body as a subject, interlaced with the self and the life, the lived body. Being able to listen to the body and interpret body cues and circumstantial information also contributed to a healthy transition. When the body with diabetes was objectified, a struggle ensued where incompatible needs were experienced and contradictory information created insecurity. The person then preferred not to interact with others but to be dependent on advice and information from the health care service.

*Conclusion:* This study showed that duration of illness was not of importance for the understanding of living with diabetes. Three years after being diagnosed, living with diabetes meant an experience both of overall balance in one's existence and of a daily struggle. Health care personnel are open to the unique experience of the person living with diabetes as well as to where the person is in the transition. Patient education in a group setting, with the goal of sharing experiences in a learning process, will be meaningful only if the person has the ability to interact with others.

Keywords: illness experience, transition, learning, diabetes mellitus, life world, phenomenological hermeneutic, lived body, patient perspective, illness and disease, chronic illness, lived experience

ISBN 978-91-7457-218-6

## List of Publications

- I. Kneck Å, Klang B, Fagerberg I.  
Learning to live with illness: experiences of people recently diagnosed with diabetes. *Scandinavian Journal of Caring Sciences*. Accepted for publication 25 November 2010
- II. Kneck Å, Klang B, Fagerberg I.  
Learning to Live with Diabetes – a Balance or a Struggle in the Lived Body  
Submitted

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## INTRODUCTION

Whilst working as a nurse at an endocrinological ward I met people newly diagnosed with diabetes and people needing care for diabetes-related complications. As a newly-graduated nurse it was easy to assume that all people everyone living with diabetes was dependent on hospital care, but with more experience I was surprised how seldom they actually seemed to need that care. This insight awoke my curiosity into gaining more knowledge of how people with diabetes learn to live with their new condition. Because experiences are important for learning, and because most people spend their lives outside hospital, it was interesting to focus on the experiences from everyday living made by persons with diabetes. Questions therefore occupied my mind concerning what it actually means to come to terms with living with diabetes as something going on in daily life. I also pondered whether and how duration of illness contributes to this process and what else facilitates and inhibits it. Further I felt that, as people living with diabetes are supposed mostly to take care of themselves, it is important that the support they are given by the health care service is experienced as contributory to their health. Even if the importance of a person-centered approach is discussed, my experience is that in reality, care is often standardized including setting goals. This made me consider whether we need to know more about what people living with diabetes experience, in order to be able to deliver more person-centered care to facilitate the process of coming to terms with the new condition. Struggling with these questions created a desire to learn more; research became my tool.

In this thesis “diabetes mellitus” will be referred to as “diabetes”. The persons interviewed will be referred to as “participants”.

## BACKGROUND

### TRANSITION FROM ONE WAY OF BEING TO ANOTHER

In life we are constantly challenged by changes; developmental, situational, organizational and in health/illness (Meleis et al. 2000). A diagnosis of chronic illness often means various changes in the body as well as in life, and includes facing many challenges (Charmaz 1983, Rush Michael 1996, Paterson et al. 1998). This can also be described as a loss of what earlier was taken for granted, a life-altering event (Kralik 2002), a fundamental loss of wholeness (Toombs 1993), loss of sense of self (Kralik et al. 2004) and loss in social and personal identity also found to be associated with feelings of powerlessness (Aujulat et al. 2007). A person experiencing change needs to deal with the situation in some way, a transition experience (Meleis et al. 2000). Transition is defined as *“a passage from one fairly stable state to another fairly stable state and it is a process triggered by change”* (Meleis 2010 p. 11).

Transition involves new skills and behaviours needed to manage the new situation, together with a changed definition of self. Uncertainty is described as being interwoven with the need for new knowledge and skills development (Meleis 2010). A medical diagnosis as an illness experience is further recognized as a marker event, an identifiable starting point for a transition (Meleis et al. 2000). In Meleis' et al. (2000) theory of transition, interrelated properties of a transition process are described. Awareness is related to perception, knowledge and recognition of the transition process. Engagement describes a person's involvement in the process seeking out information, using role models, and actively modifying activities. Both awareness and engagement contribute to a healthy transition. Change and difference are essential properties described in: *“transition is both the result of change and results in change in life, health, relationships and environments”* (p.13) and also illuminated in: *“all transition involves change, whereas not all change is related to transition”* (p.19). Transition time span refers to the flow and movements in the process. Different conditions are understood to facilitate and inhibit the process. Personal conditions are described as meanings, beliefs-attitudes, and preparation-knowledge. Indicators of a healthy transition are: feeling connected, interaction, developing confidence and coping (Meleis et al. 2000). The level of knowledge and skills relevant to a transition also influences the outcomes of a transition (Meleis 2010). Outcome is described as mastery: mastery of new skills and behaviours needed to manage a new situation and fluid integrative identities as a result of identity reformulation (Meleis et al. 2000). A successful transition is further described as one where feelings of distress are replaced with sense of well-being (Schumacher and Meleis 1994) including interpersonal relationships (Meleis 2010), different from experienced vulnerability (Meleis et al. 2000). The transition of coming to terms with living with chronic illness has been found to involve new needs in order to take care of oneself (Kralik et al. 2005, Person et al. 2010). This is important for persons with diabetes, as they provide the majority of the care themselves and are expected to be active and responsible for the daily management of their illness (Funnell and Andersson 2003, Paterson, Sloan 1994, Tang et al. 2010). A changed definition of self when living with chronic illness is defined as a reconciled self (Aujulat et al. 2008) or self-reformulation (Mayan et al. 2006). Comparing life before and after being diagnosed with an illness has been shown to be

important for a redefinition of one's identity, described as "an earlier identity partly lost" and "coming to terms with a new identity" (Asbring 2000) and clarifying one's relation to others and to on-going life roles (Whittemore 2005). To manage living with chronic illness is illuminated by Kralik et al. (2004) as coming to terms with living with chronic illness was more than doing; it was a sense of being and becoming. It is, however, not yet well understood how duration of illness contributes to the transition process when living with chronic illness (Kralik 2002, Paterson 2001, Person et al 2010, Whittemore 2005). Information and basic knowledge have been demonstrated necessary for a healthy transition when living with chronic illness (Dietrich 1996, Luyas 1991, Whittemore 2005), while others (Norris et al. 2002, Peyrot 1999) have found that gaining more information was not associated with change in relation to chronic illness.

A transition is understood as comprising distinguished phases following a chronological trajectory. Van Gennep (1960) describes transition as rites of separation, rites of transition - as in no man's land, and rites of incorporation. This is in line with the three phases which illuminate a linear process (Bridges 1933/2009): ending, losing, letting go - the neutral zone - the new beginning. Transition following a chronological order has been described by e.g. Price (1993), Hernandez (1995), Vég (2006), Whittemore and Dixon (2007) as going through different phases when coming to terms with living with diabetes. Others have found living with chronic illness as a fluctuating transition process, since a changing life world and body with illness mean continual new challenges for the person. This on-going, shifting process is described by e.g. Aujoulat et al. (2007), Kralik (2002), Paterson (2001) and Whittemore and Dixon (2008). Whittemore and Dixon (2008) also discuss the number and intensity of barriers and the available resources experienced by a person as influences on this process. The transition process is further understood as occurring in reciprocal action between the person and the environment. This is described as a person's perception and understanding of the meanings of health and illness being influenced by, and in turn influencing, the conditions under which transition occurs (Meleis et al. 2000).

Integration is described as an outcome of a healthy transition when living with chronic illness. Integrating illness in daily life has been found to be associated with being active and independent (Audulv et al. 2010, Hernandez 1995, Thorne et al. 2003) and achievement of good glycemic control (Veg 2006). The separation of illness and body from one's life is also found to enable people with chronic illness to focus on other, more valued aspects of their life (Paterson 2001), indicating that integration is the central component in living successfully with diabetes (Hernandez 1996). Integration is further described as being able to combine personal knowledge with general information, whereby the person takes ownership of his/her diabetes, focusing on living - though not at the expense of diabetes control. Integration is also described as a process in itself (Whittemore 2005, Whittemore and Dixon 2008). Hernandez (1995) found integration as the on-going process in which the two selves (the diabetes and the personal) created a person who was both mentally and physically healthy. Outcomes of integration have been described as acceptance, reconciliation, positive self-concept, as well as healing, recovery and a possibility to achieve optimum function (Whittemore 2005) and defining a new rhythm to life (Whittemore and Dixon 2008). This is in line with outcomes of transition like a potential gain, opportunity to learn, personal growth

and being skilful in control (Rotegård et al. 2010). It could also be described as mastery, understood as regaining balance between problem and assets (Rotegård et al. 2010) and understanding “*the whole picture*” (Meleis et al. 2000 p. 19).

## **DIABETES – A CHRONIC METABOLIC DISORDER**

Chronic illness is caused by pathological changes in the body that are non-reversible, permanent or contribute to residual disability (Funk et al. 2001). The term diabetes describes a group of chronic metabolic disorders characterized by raised glucose levels in blood, hyperglycaemia, caused by decreasing or lacking ability to produce insulin or to effectively use the insulin produced. Hyperglycaemia can cause serious damage in nerves and blood vessels resulting in diabetes-related complications such as blindness, kidney damage, amputation of lower limbs and cardio-vascular illnesses with a risk of early mortality (UKPDS 1998). The American Diabetes Association (ADA 2003) defines four types of diabetes mellitus, type 1, type 2, gestational diabetes and “other specific types”. Among “other specific types” LADA (latent autoimmune diabetes in adults) and MODY (maturity onset diabetes in young) can be mentioned. At least six different forms of MODY have been reported. About ten percent of people diagnosed with type 2 diabetes have a form named “Min” (mixed type 1 and type 2) (Groop 2002). With type 1 diabetes daily multiple injections of insulin are required, whereas people with type 2 diabetes sometimes manage merely with a changed lifestyle, sometimes combined with medication. Insulin is also frequently used in order to achieve good metabolic control even for people with type 2 (Socialstyrelsen 2010).

Diabetes is one of the world’s fastest growing health problems. The prevalence of type 2 diabetes world-wide is described as being of epidemic proportions. The prevalence of diabetes in Sweden is about 3-4% (300.000–400.000 persons), constituting one of the country’s endemic diseases. Type 2 diabetes accounts for 85-90% while type 1 diabetes accounts for 10-15% (ISPAD 2006, Thunander et al. 2008). Metabolic control is an important goal in diabetes care together with minimizing the impact of the disease on daily life (ADA 2003). HbA1c is the most established measurement for a longitudinal mean of the metabolic control, an increased HbA1c is strongly correlated to development of complications. Attaining a sufficient level of HbA1c could be assumed to be of interest both for the person living with diabetes and for the health care system (Ellis et al. 2004, Gary et al. 2003, Norris et al. 2001). However, studies have shown that a majority of people with diabetes do not reach their expected goal for “good” metabolic control (Loveman et al. 2003, Lundman et al. 2001, Norris et al. 2002).

While each chronic illness has problems specific to the aetiology and patho-physiology of the disease, common challenges and needs across chronic illnesses have been identified e.g. recognising symptoms and taking appropriate actions, decision-making, lifestyle management, self-care adherence to medication and going for medical check-ups (Paterson and Sloan 1994, Rankin and Stallings 1996, Thorne et al. 2003). At the same time each chronic illness makes specific demands on the person. Some mentioned for diabetes are dietary adjustments, regular exercise, glucose testing and decision-making concerning medical treatment (Hörnsten et al. 2004).

## **DISEASE AND ILLNESS – ILLUMINATING DIFFERENT PERSPECTIVES**

How people living with chronic illness experience and understand their chronic condition can be regarded as lived knowledge of having an illness (Hansson Scherman 1994), or as experiencing illness from a life world perspective (Toombs 1993). An illness can also be understood from a biomedical perspective, explaining the illness in terms of disease. Frank (1998) described these different views of knowledge as different voices; the voice of medicine and the patient's voice. Zoffman et al. (2008) found that professionals had a "disease-oriented perspective" focusing on patients' symptoms, test results and treatment. This was different from patients who had a "life-oriented perspective", focusing on reactions to diabetes in their daily life with others. This meant that patients seldom told professionals what was really difficult for them, and at the same time professionals seldom told patients what they regarded as being most difficult for the patient. However, others have found that patients can also have a disease-oriented perspective (Zoffman and Kirkevold 2005). Furthermore, Hunt et al. (1998) found that professionals used objective measurements such as Hb<sub>1c</sub> for evaluating the condition of the patient, but also as a tool for assessment of the patients' ability to control their diabetes. Patients instead referred to how they felt - which also is in line with Moser et al. (2008). Edwall et al. (2010) found that being controlled by the health care service meant being examined and then gaining insight into one's own health. In a study by Kralik et al. (2004), learning self-management was identified by professionals as structured education, whilst participants identified it as a process initiated to bring order in their lives. People living with chronic illness were also found to learn about their response to illness not by following prescribed regimes from health care staff, but by finding their own practices that fit within the context of their lives (Kralik 2002, Kralik et al. 2004).

## **LEARNING WITHIN A LIFE WORLD PERSPECTIVE – A THEORETICAL FRAMEWORK FOR THIS THESIS**

While living, humans are constantly learning - to survive, to develop but also to participate and belong to social groups - as an ongoing life long process (Jarvis 2003). For learning and understanding more, the importance of experience is raised by several e.g. Dewey (1938) "learning-by-doing", Knowles' (1975) and Kolb's (1984), learning cycle, who explore learning as experiential. Learning is also described as mainly behavioural e.g. skills learning cf. Skinner (Jarvis 2007), or as mainly cognitive activity e.g. reflective learning, cf. Piaget (1929). Learning is also understood as something which occurs in relation to others and in a specific situation, explored by e.g. Säljö (2010) and Jarvis et al. (2003) as socio-cultural learning. This is further illuminated as people's ability to make changes, context-driven and in each unique situation (Dalton and Gottlieb 2003). Jarvis (2007 p. 7) defines learning as; "*a combination of processes whereby the whole person - body (genetic, physical and biological) and mind (knowledge, skills, attitudes, values, emotions, beliefs and senses) – is in a social situation and constructs an experience which is then transformed cognitively, emotively or practically or though any combination and integrated into the individual's own biography*". This "combination of processes" has been of interest for this thesis.

Learning is regarded as a change in humans' understanding of themselves or their life world. Both Piaget and Merleau-Ponty illuminate this as changing structures. Piaget in turn describes cognitive structures (Piaget 1929) and Merleau-Ponty (1945/2002) explain this as the body schema (*schéma corporal*), structures or embodied pre-conscious habits and "*the acquisition of habit as a rearrangement and renewal of the corporeal schema*" (p.164) providing the strength to respond to a situation. When our previous knowledge no longer fits a situation, previous structures (our body schema) can no longer meet the situation and tension or disharmony will arise. A need to meet those situations in a new way raises a need for transformation of structures, (Merleau-Ponty 1945/2002), a learning experience. Schultz and Luckmann (1973) also discuss the need to expand the "*stock of knowledge*" (p.224) in order to be better prepared to deal with life. Problematic experiences raise a need to understand.

The life world, where experience is made and situations are met, becomes essential for understanding more (Dahlberg et al. 2008). Merleau-Ponty (1945/2002) described the life world as both transcendental, universal, and an everyday world where we act and respond with a natural attitude, as well as subjectively, a world of perception. We are always part of our life world and the body is the vehicle for our being to the world (Merleau-Ponty 1945/2002). Schultz and Luckmann (1973) describe the life world as a social world. They illuminate understanding as a dialogue taking place within the person as well as an external dialogue taking place between the person and the surroundings, including the environment and others.

## **PERSON – CENTERED EDUCATION**

According to Meleis and Trangenstein (1994), nursing is concerned with the process and experience related to transition. Since people are vulnerable and at potential risk during transition, nursing interventions are aimed at avoiding these risks, as well as at enhancing well-being and mastery of self-care (Meleis 2010). To facilitate the transition for people living with diabetes, patient education is performed and a holistic, person-centered approach is recommended (Socialstyrelsen 2010). McCormack and McCance (2006) describe person-centered care as working with the person's beliefs and values. This is fundamental to understanding how persons with illness make sense of their condition and also to enabling "*shared decision-making*" (p.476) and involvement in care and well-being. Telford et al. (2005) discuss this as taking into account the wider social context of people's lives as well as medical aspects. Norris et al. (2001) describe aims for education for people with chronic illness as improving decision-making, improving quality of life and also reducing unnecessary health care visits. For persons with diabetes, the goals of such education are often evaluated in terms of optimized metabolic control, HbA1C, optimized quality of life and the prevention of acute and chronic complications (Norris et al. 2002), but also in relation to realizing autonomy (Moser et al. 2008).

Interventions focusing on understanding of the illness by persons with diabetes were found to be effective in terms of metabolic control and treatment satisfaction after one year (Hörnsten et al. 2005) and five years respectively (Hörnsten et al. 2008). Others have found that one of the most important aspects of modern diabetes care is that the persons with diabetes are actively involved in their own care (Van Dam et al. 2003).

Suhonen et al. (2008) found that individualised nursing education intervention was superior to non-individualised intervention. Despite that, checklists are frequently used (Thors Adolfsson. 2008). There is a wide range of research concerning different methods of education for persons with diabetes, e.g. recording daily activity (Gleeson-Kreig 2006), frequent blood glucose monitoring (Moreland et al. 2006) and using a pedometer (Engel and Linder 2006). Gleeson-Kreig (2006) discuss whether the interaction between health care professionals and patients contributes to the changes rather than the intervention itself. At the same time Jarvis (2007) emphasizes that how people learn and make changes can never be reduced to an issue concerning methods or techniques.

## **RATIONALE OF THIS THESIS**

Mastery of new skills, behaviours and identity reformation are described as outcomes in a healthy transition. How this mastery and reformation is achieved is not yet understood in relation to diabetes. A better understanding of the transition of living with diabetes can provide knowledge which will contribute towards a holistic approach in nursing. More knowledge of what facilitates and inhibits transition will also contribute to understanding how health care services best can facilitate for people with diabetes to be active and feel responsible for their health and care. Transition is understood to be a process over time, although there is a lack of studies with a longitudinal design. Even if several studies of transition in relation to chronic illness have been conducted, few have focused exclusively on diabetes. A longitudinal design with a focus on the transition of living with diabetes will provide a new and deeper understanding of this particular transition.

## **AIM**

The overall aim of the thesis was to illuminate the transition of living with diabetes during the first three years after diagnosis, in order to reach an understanding of how better to create more person-centred care

### **Study I:**

The aim of the study is to reach an understanding of how learning to live with diabetes is experienced in the first two months after diagnosis.

### **Study II:**

The aim of the study was to illuminate the meaning of learning to live with diabetes three years after being diagnosed.

# METHOD

## DESIGN

To understand the transition of living with diabetes as a multiple, complex and diverse phenomena, a life world phenomenological approach was chosen. Life world research attempts to explore and understand the entirety of the phenomena of interest, described as grasping the meaning of phenomena, analyzing, synthesizing and then presenting them and their meaning as faithfully as possible (Dahlberg et al. 2008). To understand the phenomena of the transition of living with diabetes, a longitudinal, descriptive and interpretive design was used with the same participants, during the first three years after being diagnosed with diabetes. To explore the phenomena, interviews were conducted at a hospital, at the place of work or in the home, according to participants' preferences, and lasted approximately 45 to 70 minutes (I) and 50-70 minutes (II).

In study I participants were asked to narrate their experience of living with diabetes using the open-ended questions 'How have you experienced these first months of living with diabetes?' and 'Can you tell me about a situation where you took your diabetes into account?' When it felt appropriate I asked 'How have you experienced support during this time?', if this issue had not already been raised. No definitions of "support" or specific "situations" of interest were given. In study II the participants were also asked to narrate their experience of living with diabetes. The interviews began with the open-ended question: "How do you experience living with diabetes?" The participants were also asked to narrate situations where they had taken their diabetes into account. In both study I and II, probing questions that clarified and explored their narratives were asked when necessary; e.g. 'Could you tell me more about that?' 'What did you do?' or 'What did you feel?' The interviews were audio taped and transcribed verbatim.

### Participants

The participants were recruited from an endocrinological ward at a Swedish metropolitan university hospital. A selective sampling approach was used. Thirteen participants (26– 65 years old), both women (4) and men (9), with various social and working conditions (3 living alone, 10 living with partners, 11 working, 2 not working) and different types of diabetes (5 with type 1 and 8 with type 2) were included. All participants were able to take part in an interview conducted in Swedish. About a week after being discharged from hospital with a diagnosis, the participants were informed by letter about the longitudinal study, lasting for three years. A few days later, they were telephoned by myself and could ask questions before deciding whether they wanted to participate or not. Three persons declined to participate, and it took five months to recruit the participants. Participants were interviewed between the first and second month (I), after one year (data not used for this thesis) and after three years (II) from being diagnosed with diabetes. Before each new interview participants received both written and oral information.

## **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 participants were reassured that their participation was voluntary and that they could withdraw from the study at any time without stating a reason. The study was approved by the regional research ethics committee (Dnr 03-589) in line with the prescription of the Helsinki declaration (1996). The participants were guaranteed confidentiality and interview tapes and information on participants were stored in a secure cabinet. All interview data including quotations were number coded. The consequences for the participants enrolled in the study were considered as well as ethical dilemmas that could occur, in line with e.g. Kvale and Brinkmann (2009). I had professional experiences of the area, which is described as an advantage (Kvale and Brinkmann 2009) but also involves the risk of performing therapeutic counselling. I explained to the participants that, despite being a nurse specialized in diabetes care, the purpose of the interview was to conduct research. I was aware of the sensitive nature of the questions asked and the possibility that this could arouse existential as well as emotional feelings. At the same time, the possibility of being listened to is often raised as an important (but seldom met) need by people living with chronic illness. By being involved in the study, participants had the chance of being listened to.

## **ANALYSIS**

### **Study I**

A qualitative inductive content analysis was used. This is a method well suited to analyzing data on multifaceted, sensitive phenomena, such as lived experiences of a condition, and which also permits a variety of depth of interpretation according to the data available (Graneheim and Lundman 2004). There are various 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 itself), abstracted meaning units (interpretation of the underlying meaning), sub-themes and themes (Graneheim and Lundman 2004). All of the interviews were first read through in order to grasp the material in its entirety. The analysis continued by dividing the text into meaning units, which could consist of words, phrases or sentences; in the next steps these were condensed and abstracted, compared and interpreted into ten sub-themes and four themes.

### **Study II**

The transcribed interviews were analysed using a phenomenological-hermeneutic method, which is a process of interpretation involving three phases: naive understanding, structural analysis and comprehensive understanding. All phases involve constant dialectic movement between the whole and parts of the text, between understanding and explanation and onwards to a new understanding. The method is inspired by the philosophy of Ricoeur (1976), has been developed by Lindseth and Norberg (2004), and further described by Fagerberg and Norberg (2009). In the naive understanding phase, the text was read to acquire a sense of each interview and of the

material in its entirety (Lindseth and Norberg 2004). The structural analysis aims to identify parts and patterns of meaningful consistency and to seek explanation of the text (Lindseth and Norberg 2004). The text was divided into units of meaning, which were condensed, abstracted and then related to each other, based on similarities and diversities, in sub-themes and themes. The phenomenon was illustrated in one overall theme, two themes and five sub-themes. In the comprehensive understanding phase the entire text was taken into account. The naive understanding, the structural analysis, the authors' pre-understanding and literature, and the context of the study, were all combined into a new comprehensive understanding (Lindseth and Norberg 2004). Using a method involving interpretation of meanings enable reaching deeper knowledge than if only concerned with content. A requisite for methods using interpretation is data with rich narrative.

## **TRUSTWORTHINESS**

To establish rigour I re-examined the whole research process, and focused on being open to the phenomena as well as on critically considering methodological and theoretical decisions, further described by e.g. Morse et al. (2002). Member check has been considered but rejected; whilst participants' lived experiences have been abstracted, interpreted and de-contextualized, in line with e.g. Sandelowski (1993). A number of criteria were identified as important for enhancing the trustworthiness of the research findings, such as careful transcripts. The use of examples from participants' narratives supported the findings **(I)** and the emerging interpretation and meaning **(II)**. All interviews were also read by all authors involved in each study and findings such as emerging themes were discussed until a consensus was reached. Emerging themes and understanding were also discussed in seminars in order to achieve "organized scepticism" (Merton 1973).

## **FINDINGS**

Managing interaction with others in order to share their experiences, so important to a healthy transition when living with diabetes, was crucially dependent on the ability to interact in such situations. Interaction contributed to participants' understanding of themselves and their life world. To be able to interact, participants had to understand their body as a unique subject, and their circumstances for living as unique. Information and the glucose meter were found to contribute to an understanding of the body both as a subject and as an object. The findings in study **I** and **II** are combined and presented as a transition process, inspired by Bridges (1933/2009) and Meleis et al. (2000). This starts with the participants' experience of facing and trying to understand a changed existence, continues with daring to meet the unknown in order to understand more, and is followed by the understanding of the body and the ability to interact with others as the main conditions facilitating or inhibiting the transition. A new beginning as "the new me" was experienced when diabetes was integrated within the person and became a new way of being. At the same time, three years after being diagnosed with diabetes, the ability to integrate diabetes in one's being fluctuated and varied between participants.

### **FACING AND TRYING TO UNDERSTAND A CHANGED EXISTENCE**

The time shortly after being diagnosed with diabetes was characterized by insecurity. Much of what had earlier been taken for granted now became unknown territory (**I**). Especially the body was experienced as different from before being diagnosed, making the participants aware of a changed condition which had to be understood. At the same time, it was confusing for participants when the body was not experienced as different. There was a new need to prioritize the body, but the participants also became more aware of their entire existence and needed to allow themselves more time and space than earlier. Their previous way of life had to be changed, which was experienced as both negative and positive (**I**).

It became important to listen to, follow body signs and to reflect. At the same time it was tiring to focus on what had earlier been taken for granted as well as on the illness as such (**I**). Participants were occupied by constant decision-making about seeking information, evaluating their earlier lives, recognizing the need for changes and considering what was possible to change. Even if they had previously been aware of the benefits of changing certain behaviours to improve their health, this now felt more credible and important. The body had "talked" and showed that it was time for change, e.g. working less, cutting down sugar intake, eating healthier and more regularly (**I**).

### **DARING TO MEET THE UNKNOWN**

Shortly after being diagnosed, participants consciously exposed themselves to different situations, trying out different activities e.g. they went out for a drink, tried different food, and physical activity. At the same time participants gained experience. Situations that were "unplanned", when something occurred that was not expected, provided

important experiences. Finding new routines in life was a way of managing the changed situation, although when routines could not be followed, “unplanned” situations occurred. Participants were then forced to think, act and reflect, resulting in a learning experience. At the same time, planning became important for managing the changed situation. Participants tried to predict what was going to happen, and, together with following routines, this was a way of feeling less insecure (I). In both studies, routines were found to be important in making life easier, by giving structure to daily life and as reminders, guaranteeing that self-management was not forgotten (I, II). After three years, routines were also found to be too regulatory and relaxing routines was positive, being free to do what one really wanted. This meant putting diabetes aside, pretending it did not exist, but also feeling that relaxing routines meant trying and discovering new things, e.g. other food, other types of exercise in order to feel healthier (II).

### **FACILITATING THE TRANSITION BY UNDERSTANDING THE BODY AS AN OBJECT OR A SUBJECT AND BY USING THE ABILITY TO INTERACT WITH OTHERS**

The body contributed to the transition process and was in many ways instrumental for learning more. It was through body cues and reactions that the illness could be understood and different situations be responded to (I). Shortly after being diagnosed, the changed life and body had to be reflected upon and understood cognitively, by reflection and by questions raised by participants and others (I). Three years later, cues from the body triggered an automatic pre-formed procedure, enacted without reflection. Participants were familiar with what was happening in each particular situation and knew what to do. The body was then understood as unique, as a subject, involved in the “new me”. Understanding the body implied taking into account earlier experiences as well as the specific situation. Listening to the body was a way of feeling good in general, and taking care of diabetes had come to mean taking care of the entire self (II).

The body with diabetes was also regarded as an object that could be understood through objective measurements. Others, mainly doctors or health care staff, became important because they had the general knowledge and could provide objective measurements relating the condition of the body. This was narrated as an object, separated from the self, and was important especially when participants experienced insecurity regarding their own interpretation of body cues. At the same time, earlier or more general information needed modification when changes occurred, and not being able to do so would lead to a feeling of insecurity. It became necessary to hold on to what one already knew or had been told, even though it this felt contradictory - a point raised both in study I and II.

Shortly after diagnosis, the glucose meter was found to be an exclusively valuable tool, a resource with which to understand bodily reactions. It was important to provide objective measurements in order to confirm a feeling or an interpretation of body cues (I). Three years later the glucose meter was still felt to be necessary; enabling participants to be more flexible, especially when findings showed major deviation from what was experienced as being ordinary. At the same time, the glucose meter was

experienced as an obstacle to listening to the body. There was a risk of acting according to the measurement results instead of listening to and following body cues (II).

Shortly after being diagnosed, information was important in order to understand more. It was, however, hard to find the energy to read information and to understand its implications. Information from the health care service was found to be easy to rely on and to grasp. Plain and simple information was appreciated but at the same time information needed to be applicable to the participant's own circumstances. It could be contradictory if information was too general; information had to answer one's own questions (I). Listening to others' experiences and advice shortly after diagnosis, especially from those not having diabetes, was experienced as tiring and irrelevant. Participants became self-centered and ignored what was said. Three years later, one's own interest for certain topics served as guide in choosing when and what to read, experienced as enjoyable but also contributory towards living with diabetes (II). When participants had more experience and knowledge, they listened to what others had to say and picked up what was relevant for themselves. Shared experience also contributed to their own and others' understanding. Participants also experienced that others let them be more independent in taking care of themselves, which meant feeling trust in being capable to deal with the illness, but it was also frustrating to have to remind others of one's special needs (II).

Shortly after being diagnosed (I) health care staff were experienced as important for the participants, being knowledgeable and providing reliable information. At the same time, health care staff were available when participants needed them, but sensitivity and willingness to focus on participants' experiences and questions were prerequisites for being appreciated as a partner (I). When participants were expected to organize their own care meetings, especially when different care settings were involved, health care staff were experienced as having let participants down (I). Three years later, participants had in many ways chosen to be independent from the health care service; they preferred to get on with their own life and were able to do so, which meant that health care staff became less important. Increased security meant that participants were more critical both to the health care system and staff and towards other people in their surrounding. Participants chose to whom they wanted to talk and listen (II). At the same time, there were periods in their life when they had to be more dependent on health care. When crucial life events arose or the body cues no longer were familiar it was harder to live with illness (II). Diabetes then demanded attention that was even more difficult to offer when life in general or the body seemed to absorb all available energy (II). It was also difficult to regain access to the health care system. Participants also experienced having needs for which the health care service was unable to help. Relatives, friends and family were the ones they turned to instead (II).

## **DIABETES AS INTEGRATED, AS A NEW WAY OF BEING**

Shortly after diagnosis (I) diabetes was in focus and participants easily picked up situations to narrate. Three years later (II) it was not as obvious for participants to recognize these situations. Diabetes was regarded as being integrated within the person when the illness was involved in the body and in life and had formed a new way of

being. Living with diabetes was then overall experienced as easy; it was not possible to identify which elements in life were influenced by diabetes and what life would be like without having diabetes; diabetes was a part of the “new me”. Integrating diabetes implied an overall feeling of balance, making everyday choices and feeling that diabetes was involved in them, without it being regulatory. The ability to integrate diabetes and experience balance varied among participants. Demanding life events or changes in body condition could also make it harder to experience balance.

Participants also fluctuated between being dependent on routines and integrating illness into their existence. **(II)**. When diabetes was objectified, separated from one’s existence, routines such as certain behaviours became important for maintaining control of self –management, for example; eating breakfast only on working days. Certain routines were connected to particular life events, so when situations changed routines could not be carried out as usual. A struggle was experienced as a constant sacrifice, a contradiction between having to choose in a particular situation between what one thought would benefit the body and/or the illness and what one actually wanted or thought was possible to carry out **(II)**.

# DISCUSSION

## DISCUSSION OF FINDINGS

The findings will be discussed by illuminating a healthy transition as experiencing an expanding life world. I also discuss how transition was established, as a process of learning.

### **Experiencing an expanding life world**

With short experience of living with diabetes, participants were self-centered and had an overwhelming insecurity. Even in a common situation they could not take part, and their life world had in many ways “shrunk”. With more experience and increasing confidence, participants could experience others around them and choose with whom to interact. Important requisites for a healthy transition were being able to manage contradicting information and others’ experiences, as well as being able to interpret information from one’s own circumstances. Managing interaction meant that the life world was expanding, that participants could experience more, learn more and be more alive. Interaction as being important for a healthy transition, also described by Meleis et al. (2000) and as “moving on” in the process of living with chronic illness (Kralik et al. 2005).

In this thesis, the ability to move on in the transitional process was associated with the understanding of the body as a unique subject. The body is tightly interlaced with oneself and one’s circumstances for living: a changed body also meant a changed life and self. When it was no longer possible to separate diabetes from oneself or one’s life, diabetes was found to be integrated within the person, becoming the participants’ new way of being. Living with diabetes was then overall experienced as easy. Understanding the own body as a subject also meant feeling that one could only be responsible oneself for the care of diabetes, even if other people contributed in different ways. Integrating diabetes then implies the focus on either the body or self or life depending on the situation; all in line with Whittemore (2005) and Thorne et al. (2003). This interaction of body, mind and life world - understood in relation to each other, constantly affecting each other and our understanding - is further described as the lived body (Merleau-Ponty 1945/2002). Later on in the transition process participants recognized themselves as being different from earlier, showing this in narratives of “the new me”, as well as in the world presenting itself as different. Things that participants had not noticed before suddenly acquired a new meaning e.g. appreciating nature or relationships with others. This is further illuminated by Jarvis (2007) - learning as a reciprocal action within the person and his world or as a social-cultural phenomenon also described by Schultz and Luckmann (1973). This reciprocal action between changes in the life world and the person is by Dahlberg et al. (2008 p.6): *“the life-world is thus a reality which we modify through our acts and which, on the other hand, modifies our actions”*.

When diabetes was integrated in the lived body, freedom was understood as being able to do what one wished to. It was implicit that illness was involved in choices and every day decision-making. It was regarded as something natural, seldom needing to be reflected upon; it was just the way of being. Integrating diabetes in the lived body also

meant having achieved an overall balance between the needs of the physical body with personal wishes and what felt possible within the circumstances for living. Merleau-Ponty (1960) describe this as experiencing harmony “*between what we aim at and what is given, between the intention and the performance - and the body is our anchorage in a world*” (p.144). The participants in this thesis also experienced a balance between what one wants to do and what one thinks one should do (Andersson et al. 2008) or between what one wants and what is socially accepted (Lin et al. 2008). Balance can also be understood as well-being or health (Newman 1994), instead of experiencing a struggle between different incompatible needs, a continuing bargain where the person always has to exclude something, unable to achieve coherence; this is also described by Schultz and Luckmann (1973). Audulv et al. (2009 p. 283) describe this as an “*inner negotiation between perspectives, e.g. social needs vs. medical needs*”.

When the body was objectified, the body with diabetes could be put to one side and neglected. Freedom was then ignoring diabetes which at the same time meant experiencing a struggle. This was especially true when other aspects of life or the preservation of one’s previous existence were more important, also supported by Johansson et al. (2009). Others, mainly doctors, became important in the understanding of the body with diabetes. However, objectifying the body could also be a way of being in charge of one’s life and not allowing the body with illness to rule one’s existence (Paterson 2001). Merleau-Ponty (1960 p.90) argue that the body can never be an object; “*it is neither tangible nor visible in so far as it is that which sees and touches. The body therefore is not one more among external objects, with the peculiarity of always being there*”(p.92). Furthermore the body is “*to say that it is always near me, always there for me, is to say that it is never really in front of me, that it is with me*”. Moving from struggle to balance was, in the present thesis, understood as moving forward in the transition process of living with diabetes. Integrating diabetes in the lived body was understood as a healthy transition in contrast to increased vulnerability- also described by Meleis et al. (2000) - in this thesis experienced as a struggle and as dependency.

### **The transition was established - as a process of learning**

The early stages of the transition process were dominated by understanding as a cognitive phenomenon, even if the body demanded recognition with its new way of being. Understanding was mainly achieved by reflection of one’s own experiences along with objective measurements and general information. With more experience, understanding became something within the body, meaning that situations did not need to be reflected upon but were instead met with a bodily understanding. When a situation was met with a bodily understanding, living with diabetes was easier than before, demonstrating the replacement of a routine (behaviours pre-formed in different life events) with a habit. Habits integrated within the person make us act without using our energy. When diabetes was involved in the participants’ habits, it facilitated their being to the world cf. Merleau-Ponty (1945/2002). Habits enable focusing on more comprehensive goals, such as living the wanted life, as experienced later on in the transition process, while just managing everyday life was more prominent early on. Schön (1987) suggests habits as “*knowing-in-action*”, an intuitively performed management in daily life where the understanding or knowledge is in the perception or action itself, enacted without reflection. Information had been personalized knowledge,

understood from one's own condition, also described as an embodied knowledge (Merleau-Ponty 1945/2002 p.166) "*it is knowledge in the hands, which is forthcoming only when bodily efforts is made, and cannot be formulated in detachment from that effort*". The ability to modify information to one's own circumstances was crucial for a healthy transition. This is also understood as moving from a disease-oriented perspective, through an illness-oriented perspective and onwards to a life-oriented perspective. This understanding, knowledge unique to one's own circumstances involved within the person, is further described as "personal-specific-knowledge" (Zoffmann et al. 2008) or "what works for me" (Price 1993). Combining personal specific knowledge with general advice is important to being active in a healthy transition process (Thorne et al. 2003). This differs from following prescribed regimes, being unable to modify them according to one's own circumstances, which has been found to be associated with passivity in the process (Paterson and Thorne 2000, Vég 2006). Mainly performing recommended behaviours was found to be associated with feeling that others were responsible for the illness (Auduly et al. 2010). Hernandez (1996) discussed this as "the ownership of diabetes" belonging to the domain of the health care service. Edwall et al. (2010) found that being controlled by the health care service also meant feeling safe, and an appraisal of the condition of the body was important for patients to feel involved in their care.

The glucose meter was found to both facilitate and inhibit body listening. Body listening, including the ability to interpret body cues, was an important prerequisite for moving on in the transition process, as also found by others (Hernandez 1995, Price 1993, Rush Michael 1996). This is further described by Paterson (2001) as a paradox, the need to pay attention to the body and illness in order not to have to pay attention to the illness. As a contributing tool for body listening the glucose meter facilitates the understanding of the lived body with diabetes but can also additional objectifying of the body with diabetes.

Experiencing and reflecting the environment is well in line with different theories of adult learning e.g. Dewey (1938), Knowles (1975) and Kolb (1984), as well as with studies concerning transition cf. Kralik (2002). Exposing oneself to different unfamiliar situations was also important and crucial for learning more as a dialogue within the person, even though these situations were associated with insecurity, or as Merleau-Ponty (1945/2002) describes disharmony. With more experience, learning was gained through interaction with others and sharing experiences, which was found to be enjoyable and contributed to the ability to live with diabetes. This demonstrates learning as social-cultural phenomena (Schultz and Luckmann 1973, Säljö 2010).

With limited experiences participants reflect in connection to different situations, reflection-in-action, while with more experience, participants also reflect-on-reflection (Schön 1987), looking back, remembering and understanding how they had changed their way of thinking and acting. Short after diagnosis the participants in this thesis reflected on daily life experience as a result of trial and error, as also raised by Kralik et. al (2004). Zoffman et al. (2008) also found that reflection helped patients with diabetes to gain insight into their own attitudes towards illness and changes. With a changed existence, participants experienced being challenged by many choices, most prominently shortly after being diagnosed. At the same time a need arose for

knowledge and experience to enable choices and to interpret the meaning of different options. The lack of knowledge and experience was found to be a contradiction; they needed experience to be able to gain information and at the same time needed information to be able to make experiences understandable. Not being able to modify information according to one's own circumstances, or finding information as contradiction, meant insecurity when handling certain situations. Awareness of change and engagement in the transition process is also discussed by Meleis et al. (2000) and Westra and Rodgers (1991) as contributing to a healthy transition.

One's ability to live the desired life and to carry out changes was not only restricted to the physical body, as experienced early in the transition process. Instead the life world, the routines one associated with having diabetes, and one's personality were all important for how participants experienced themselves and their ability to make changes. This is further illuminated by Merleau-Ponty (1945/2002) as the intentional arc, a personal frame of references, which a person brings into a situation. Routines were in the present thesis found to both facilitate and inhibit the transition: facilitating by giving structures to daily life but also limiting living the desired life. Routines which prepare and proactively modify activities are described as contributing to engagement in the transition process (Meleis et al. 2000). At the same time Rush Michael (1996) found that participants with different chronic illnesses replaced previous habits with routines which also constantly reminded the participants of the impact of the illness.

Meleis et al. (2000) describe the importance for a healthy transition of feeling connected to other people and to the health care service. The findings from this thesis show the importance of feeling connected - not only in relationship with others but also to one's life world - in order to be secure again. Daring to meet the unknown was therefore crucial to learning more but also tiring, and the alternative of being able to focus on living the desired life was appreciated. This is further discussed by Barroso (1995) as a human need for confidence without a constant effort to understand one's existence, also described as a need to focus on what is important in life (Paterson 2001, Whittemore and Dixon 2008). At the same time, when change associated with insecurity occurred, a new need arose to understand more, showing that the healthy transition towards balance fluctuated due to changing circumstances in body or life also illuminated by Paterson (2001) and Whittemore and Dixon (2008).

## **METHODOLOGICAL CONSIDERATIONS**

Rigour is of major importance for conducting good research, and how rigour was established in this thesis will be discussed in this section. As the researcher's ability to conduct good research is of vital importance for the trustworthiness of the study, analysis and interpretation will vary with the orientations of each investigator (Sandelowski and Barroso 2003) and according to Ricoeur (1976) there is always more than one way to interpret a text. I have been aware of that, as well as of the reciprocal action between the data and myself, described by e.g. Jarvis et al. (2003). Ricoeur (1976) states that there is always a point when the text turns itself against the reader and asks the reader questions instead of the reverse; this is something I also have experienced, especially in the comprehensive understanding in study II.

## **Participants**

All participants (n=13) participated for three years, which is considered advantageous for this thesis. In qualitative research the issue is not the number of participants, but rather the quality of the data, the divergence of the phenomena of interest and the richness of the narratives (Dahlberg et al. 2008). The selected sample approach enabled a variation in parameters such as age, working condition or gender and a diversity of the phenomena was achieved in order to increase the possibility of grasping the meaning of the phenomena (Dahlberg et al. 2008, Patton 2002). When participants were recruited to the study lab results indicating the type of diabetes were not available. The type of diabetes was not considered of main importance, since the focus was on the experience within the transition of being diagnosed with diabetes as a chronic illness with the inability to achieve normal glucose levels. ADA (2003) also suggests that it is less important for patients to label the type of diabetes than it is for them to understand the reason for hyperglycaemia and how to treat it effectively.

Medical treatment was then regarded as a condition that enhanced grasping the meaning of the phenomena. In our data analysis, it was interesting to note that among the participants one person had an unclear diagnosis though it was considered to be related to an earlier pancreatitis. Medical treatment could also vary for some of the participants during the period of the study. Participants diagnosed with type 1 diabetes had periods without insulin. For participants with type 2 diabetes, medical treatments changed during the period of the study. I was also surprised how differently participants understood their diabetes compared to what is explained in textbooks. In this study there was no difference in relation to the type of diabetes when narrating about the need for life style changes or about anxiety for hypoglycaemia.

It is to be noted that, even if participants were recruited to the study in connection to a hospital visit when they had been diagnosed with diabetes, it was later found that some had previous experiences of being ill. Some also developed other conditions during the period of the study. This has probably influenced their transition process of living with diabetes. Meleis (2010) also claims that transition in relation to chronic illness influences, and is influenced by, other transition processes going on within the person. Learning is further understood as created within a cultural and contextual meaning (Jarvis et al. 2003), so it is important to note that this thesis is based on interviews with participants all living in one geographical area. This must be considered as a limitation of the study, just as the fact that all participants were recruited after a hospital visit may have influenced their awareness and engagement in the transition process.

## **Interviews and analysis**

The ability to perform interviews is a skill which needs to be experienced and learned. My ability to conduct interviews was probably one reason why interviews appeared deeper and richer in narratives in study II compared to study I. Also the participants' expectations could contribute to the different quality of the interviews. In study I participants could ask; "is it this you want to know?" or give detailed descriptions of their different glucose levels. In study II participants were more comfortable "just" narrating their experiences of living with diabetes or narrating life situations. This

demonstrates that participants also have an expectation, a pre-understanding (Dahlberg et al. 2008), of what the situation (in this case the interview) would be about.

It seemed appropriate to ask for situations in daily life where diabetes had been taken into account. In study **II**, however, some participants found this problematic. Even if the analysis of the narratives showed that they always took diabetes into account, they themselves did not recognize it any longer. Neither was the word “learning” often used by the participants, although in the analysis the learning became apparent. This is in line with Kolb (1984) who discussed learning as often being spontaneous and unconscious for the person. Therefore, it was considered appropriate to ask about situations that the participants had experienced in connection with having diabetes, rather than directly about the learning process as such (“how/when have you learnt that?”) - often named as turning points (Rasmussen 2007). Asking such questions could have provided interesting data to this thesis. With the findings and understanding from this thesis, one can question whether it would have been more appropriate in study **II** to ask about experiences concerning “situations that have affected you and which you had to handle in some way”. This would decrease the risk of separating and objectifying an integrated illness (Tang et al. 2006, Thors Adolfsson 2008). Meleis et al. (2000) emphasize that, to understand a specific type of transition, it is also necessary to consider the patterns of all significant transitions of importance for the person.

In study **I** the analysis concerned content, whilst in study **II** it concerned meanings. In study **II** the interview data were rich narratives, so it was possible to “dig” deeper in the data, being able to use the hermeneutic circle (Ricoeur 1976). A strength of the phenomenological hermeneutic method was the possibility of combining both my pre-understanding and my interpretation of findings into a new understanding together with literature in adjoining areas (Ricoeur 1976). The difference of depth in data between studies **I** and **II** made it possible to choose different analytic methods, which was regarded as an advantage since an interest in illuminating meaning emerged after study **I**. A phenomenological attitude, including both bracketing and the interest for participants’ own understanding of themselves and their life world, was used throughout the entire research process for both studies **I** and **II**, as well as in the epistemology and ontology connected to life world research.

The phenomenological attitude means being aware of one’s own pre-understanding so as to not be too quick in understanding the phenomena. At the same time we cannot do a transcendental reduction, only a bracketing of the *epoché* (Dahlberg et al. 2008, Morse et al. 2002). My own pre-understanding was shown in the question; “what kind of support have you received?” At the time I found that question to be “open-ended” (Kvale 2007), especially as I did not give any definition of “support”. However, the assumption that support would be essential for the participants showed my pre-understanding, probably derived from being a clinical working nurse. Leaving the nurse perspective for the perspective of a phenomenological researcher must be done through learning, in my case more in a perceptive than a cognitive fashion. An example:  
*During his first week in school I attended school lunch with my son in the canteen. Sitting a few tables away from my son and his classmates, I observed that the principal of the school came to their table and introduced herself. She also told them that she always ate in the canteen and that they could come and talk to her whenever they*

wanted. She was face to face with the children, looking at them and listening to their response. She asked one of the children for a napkin before wishing them all very welcome to the school. When we walked home I thought about what a positive impression the principal had made on me, and I could not remember ever having talked to the principal when I was a child. I therefore said to my son: "How nice of the principal to come and talk to you". He then answered me: "Yes, she needed a napkin". Then I understood what I had read several times, that we all bring our pre-understanding which makes us understand each situation differently.

Earlier knowledge and experiences are both advantageous and disadvantageous for being able to understand more. Before analyzing data for study II I found myself expecting that the main themes from study I would also be important issues in study II. At the same time I had not deepened my knowledge of the theoretical part of the transition process to be able to predict the understanding which emerged. Instead the analysis became a purely inductive experience, seeing the comprehensive understanding emerge from the findings together with existing research and other literature. Not being well initiated in the topic beforehand contributes to more independent research, and protects the integrity of the research (Forsman 2002).

With the main findings showing the importance of focusing and understanding the own body as well as the need to integrate diabetes in one's unique life situation, one can raise the question of whether this is obvious, something we already know. In phenomenology this is named the natural adjustment, the taken-for-granted that surrounds us on a daily basis. Further, one can then ask, is it meaningful to do research on something about which we already know? "Bracketing" (Dahlberg et al. 2008) or accomplishing *epochée* (Lindseth and Norberg 2004) is then understood as enabling us to see and understand something in a different way than previously. Merleau-Ponty (1945/2002) tell us that we have to take a step back so as not to be absorbed by conventional understanding of the phenomena. With this in mind, I would say that the use of a phenomenological attitude for this thesis has made a contribution to the understanding of the transition of living with diabetes.

## CONCLUSION AND CLINICAL IMPLICATIONS

Managing interaction with others in order to share their experiences, so important to a healthy transition when living with diabetes, was crucially dependent on the ability to interact in such situations. Interaction contributed to participants' understanding of themselves and their life world. To be able to interact, participants had to understand their body as a unique subject, and their circumstances for living as unique. The illness was then interlaced within the body, self and life, the lived body. When diabetes was integrated in the lived body, living was in general experienced as simple since decisions made always involved having diabetes. Contradictory information and others' experiences were manageable, since information always had to be personalised to become meaningful. Being able to listen to one's body and to interpret body cues and information from one's own circumstances were also contributory to being independent from health care services. When the body with diabetes was objectified, a struggle ensued where different incompatible needs were experienced, and contradictory information created insecurity. The person then preferred not to interact with others, but to be dependent on advice and information from health care staff. It was also found that when participants had limited experience of living with diabetes, self-centredness, reflection and routines were important factors in managing a changed existence. With the findings from this study, listening to how people talk about their body, as an object or as a subject, will increase the understanding of how they integrate diabetes in the lived body.

This study showed that duration of illness was not of importance for the understanding of living with diabetes. Living with diabetes three years after being diagnosed meant to experience both an overall balance in one's existence and a daily struggle. Health care staff should be open to the unique experience of the person living with diabetes as well as to where the person is in the transition process. With the findings from this study, patient education in a group setting, with the goal of sharing experiences in a learning process, will be meaningful only if the person has the ability to interact with others.

## ACKNOWLEDGEMENTS

There are several people that I want to thank for helping me carry out this thesis.

The participants in this thesis: thank you for taking your time and sharing your experiences with me.

Assistant Professor **Birgitta Klang**, my supervisor: this project would never have started, resulting in this thesis, if it hadn't been for you. You introduced me to the topic, a topic we are both interested in, and have been able to explore together. I am deeply grateful for that since my exploration of the nature of human learning has enriched my professional and personal life. I have also always felt that you care about me, not only as a student but as a person, and this I deeply appreciate.

Professor **Ingegerd Fagerberg**, my co-supervisor: this thesis would probably not have looked like this at all if it were not for you. You introduced me to the core of methodology and the concepts and meanings of philosophy. You made me question everything I thought I knew, but never doubted in my capability to carry out this thesis. You have always let me take the decisions on how fast to move ahead, never forgetting that other things in life can be more valuable. I appreciate that and your endless patience with reading all my documents.

**Gunilla Edvinsson**, my mother: this thesis would not have been done at this time of my life if it weren't for you. You have enabled me to improve in this topic and at the same time helped me to live up to my expectations of my own motherhood. You have taught me that, just as learning is, motherhood is life-long too, a gift which needs to be appreciated and taken care of.

Further I want to thank my **colleagues at Ersta Sköndal University College**. You all have a common interest in learning and understanding, which creates a supportive environment for carrying out this thesis. Thank you all for sharing my frustration, and sometimes my joy, connected to this thesis. Especially, I want to thank: **Mikaela Karlstedt**, a newly-won friend, for all your support during this time of my life, **Gunilla Johansson**, PhD, for sharing your experiences and making me laugh, **Ida Carlander** for helpful suggestions on my first article, **Chi Persliden** och **Jeanette Timgren** for taking such good care of me when trying to be a teacher, **Eva Elmberger**, PhD, and Professor **Jennifer Bullington** for critical examination of this thesis, and introduction to the theory of transition and Merleau-Ponty.

Professor **Berit Lundman**, **Åsa Hörnsten**, PhD, **Ulf Isaksson**, PhD, all at Umeå University, for your most valuable points of view on this thesis.

**Nina Ringart**, KIDS, for always being so helpful with all the several documents through the years.

**David Cluer** for linguistic support.

My friends **Ulrika Persson**, **Karin Emtell** and **Lisa Enar** - we share our lived experiences through different phases of our lives, including sadness, happiness and books.

This thesis has made me understand that some people have been especially important for my own learning process and development. Thanks go to **Britt Sandstrom** (teacher 4th to 6th grade), **Jan Clevemar** (mathematics and science teacher at upper secondary school), **Else-Marie Andréé Sunderlof** (teacher at the Red Cross University College) **Ingrid Daiss** (first line nursing manager).

Finally I want to thank my family. **Magnus**, my husband and friend throughout life, even though I have never been able to explain this project properly, and though you have often had doubts about its outcome, you have encouraged me to do what I wanted anyhow. Together we share joy and responsibility of our children, **Pelle, Ida, Tyra**; living with all of you makes me feel very rich. My sister **Jenny**, her husband **Tomas** and my nieces, **Edith** and **Vera**, also contribute to the joy of my daily life.

My father **Jan Edvinsson**: I wish you were still with me, sharing my life and this event.

# **POPULÄRVETENSKAPLIG SAMMANFATTNING**

## **ATT LÄRA SIG LEVA MED DIABETES- SOM ATT FÅ SJUKDOMEN ATT BLI EN DEL AV DEN MAN ÄR**

### **BAKGRUND**

När en person får en livslång sjukdom, som diabetes, innebär det för de allra flesta en förändring. Tidigare studier har visat att denna förändring omfattar både kroppen, det dagliga livet samt personens syn på sig själv. Att lära sig nya färdigheter och beteenden för att kunna möta denna förändring kan beskrivas som en transitionsprocess. En transition beskrivs som processen mellan ett relativt stabilt tillstånd till ett nytt relativt stabilt tillstånd, som startar med en förändring, exempelvis en sjukdomsdiagnos. Resultatet av en hälsosam transitionsprocess beskrivs som ökat välbefinnande, personlig utveckling och en förmåga att få balans i tillvaron. En transition kan också resultera i en ökad utsatthet och lidande. En viktig uppgift för sjuksköterskor är att bistå personer som genomgår en transition till att öka möjligheterna för en hälsosam process.

Diabetes är ett samlingsnamn för flera typer av diabetessjukdomar där de två vanligaste formerna benämns typ 1 och typ 2. I Sverige är diabetes en folksjukdom och liksom i stora delar av övriga världen insjuknar allt fler i diabetes. Diabetes är en livslång sjukdom där kroppens förmåga att reglera blodsockernivån av olika anledningar är försämrad eller har upphört. Detta leder ofta till förhöjda blodsockernivåer; försämrad metabol kontroll som är starkt relaterat till en ökad risk för komplikationer i kärl och nerver vilket bland annat kan resultera i hjärtinfarkt, stroke, fotsår samt påverkan på ögon och njurar. Detta göra att personer med diabetes behöver vidta olika åtgärder för att sköta sin sjukdom, något som de allra flesta gör till största delen på egen hand. En person med diabetes förväntas att vara aktiv i sin behandling och egenvård vilket medför att personen behöver ny kunskap och lära sig nya färdigheter. För att bistå personer i att tillägna sig denna kunskap erbjuds patientundervisning. Önskade effekter av patientundervisning är förbättrad metabol kontroll, ökad självständighet, färre sjukhusbesök och ökat välbefinnande. Tidigare studier har visat att för att vara effektiv måste undervisningen utgå från ett personcentrerat förhållningssätt vilket innebära att patientens egna upplevelser och värderingar är i fokus samt att patienten är aktivt involverad i lärandet. Trots detta har studier visat att den allra största delen av patientundervisningen utförs efter checklistor med förutbestämde mål. En stor del av de personer som idag har diabetes når inte de mål som är uppsatta för så kallad god metabol kontroll.

### **SYFTE**

Det övergripande syftet med denna LIC avhandling har varit att belysa transitionen att leva med diabetes för att få en ökad förståelse för hur man bättre kan möjliggöra för en mer personcentrerad vård.

## STUDIERNAS GENOMFÖRANDE

Två delstudier omfattar avhandlingen. Tretton personer har ingått i både delstudie **I** då personerna intervjuades inom de två första månaderna efter diagnos och i delstudie **II**, då samma personer intervjuades tre år efter diagnos. För att öka möjligheten att förstå så många aspekter som möjligt av det studerade fenomenet, så använde urvalsförfarandet maximal variation, vilket innebar att personer av olika kön, ålder, social bakgrund, utbildningsnivå och typ av diabetes ingick i studien. Intervjufrågorna var de samma och personerna ombads berätta om hur de upplevde att leva med diabetes samt att berätta om situationer där de upplevt att det blivit tydligt att de haft diabetes. Intervjuerna skrevs ner ordagrant och analyserades sedan, i delstudie **I** med kvalitativ induktiv innehållsanalys och i delstudie **II** med fenomenologisk hermeneutik. Studierna är gjorda utifrån en livsvärldsansats vilket innebär att personernas upplevelser och erfarenheter har fokuserats.

## RESULTAT

Resultatet av delstudie **I** presenterades i följande teman:

”överrumplad av en ny tillvaro”, ”kroppen tar plats i livet”, ”olika sätt att lära” och ”sjukvården - en nödvändig partner”.

Resultaten av delstudie **II** presenterades i följande teman:

”erfarenhet för att förstå vad som är frihet och kontroll för en själv”, ”att lösa livspusslet - en delikat balans att skapa det önskade livet” och ”behovet av att ha kontroll över den egna hälsan”.

Sammanvävning av resultaten från delstudierna visade att personerna kort tid efter diagnos upplevde stor osäkerhet då den tidigare kända tillvaron var förändrad. Att förstå hur kroppen reagerade blev viktig i att förstå diabetesjukdomen. Personerna upplevde att diagnosen medförde behov av förändringar av olika slag, ex. gällande kost, motion, arbetssituation osv. Samtidigt upplevde de en brist på kunskap och även andra hinder för att genomföra dessa förändringar. Kort tid efter diagnos upplevde personerna i studien andras råd och erfarenheter som stressande, särskilt var motstridiga uppgifter eller information förvirrande. Personerna blev självcenterade, gjorde egna erfarenheter och reflekterade på egen hand. Att våga prova och utsätta sig för olika situationer var viktiga för att skaffa sig erfarenhet. Vårdpersonalen blev viktig då de har en enkel och tillförlitlig information. Att vårdpersonalen var uppmärksam på personernas egna upplevelser och frågor var viktigt för att vara uppskattad. Blodsockermätaren blev ett viktigt redskap i att förstå kroppens reaktioner och för att få objektiva svar på det personerna upplevde.

Med mer erfarenhet (**II**) var innebörden av transitionen att leva med diabetes att ha kunna integrera diabetes i kroppen, livet och jaget det vill säga diabetes sjukdomen hade blivit en del i personens nya existens. Kroppen blev ett subjekt och att må bra handlade då om att hela personen skulle må bra. När beslut i det dagliga livet skulle tas så var konsekvenser av sjukdomen involverad i dessa. När diabetesen var integrerad i personens hela existens blev det ett nytt sätt att vara och hantera livet på. Kunskapen blev då integrerad i personen och personen själv kände att endast hon eller han kunde vara ansvarig för sin hälsa där diabetesen var en del. I delstudie **II** framkom också att kroppen med diabetes kunde förstås som ett objekt, där andra, oftast hälso- och

sjukvårdspersonal, blev viktiga då de genom objektiva mätningar kunde tala om hur kroppen mådde. Detta var särskilt framträdande då en person inte lyssnade eller förstod kroppens signaler. Generell information blev viktig men samtidigt upplevdes osäkerhet när informationen inte kunde anpassas till de egna unika förutsättningarna. När kroppen var objektifierad så kunde kroppen sättas åt sidan, ”glömmas bort” då frihet var att slippa ta hand om diabetesen och kroppen, detta innebar samtidigt en kamp då personen upplevde en motsättning mellan olika behov som inte alla kunde tillfredsställas. Rutiner var viktiga i båda studierna, för att säkerställa att egenvården blev utförd och för att ge struktur i det dagliga livet. I delstudie II kunde rutinerna ha blivit till vanor, som en del av personens existens, och utfördes då automatiskt, utan behov av reflektion. Samtidigt kunde rutiner upplevas begränsade och utgöra hinder för att leva det önskade livet. Blodsockermätaren var viktig även efter tre år, för att förstå kroppen, men att använda sig att blodsockermätaren kunde också innebära att personerna lät sig styras av mätvärdena istället för hur de mådde vilket kunde resultera i en spiral av åtgärder som sedan visade sig vara onödiga. Med mer erfarenhet blev vårdpersonalen mindre viktiga än tidigare, personerna hade då hittat andra personer som de delade sina erfarenheter med. För att kunna interagera med andra och ta till sig motsägelsefulla erfarenheter behövd dock personen känna sig trygg i sin egen förståelse av sin egen unika kropp och den egna livssituationen. Personen kunde då ”plocka ut” det som kändes relevant för dem själva. Samtidigt innebar förmågan att kunna ta del av andras erfarenheter en större tillgång till livet då personerna upplevde nya saker både i relation till dem själva, nya prioriteringar och värderingar men också nya saker i livet, som naturen och betydelsen av relationer med andra.

## **SAMMANFATTANDE REFLEKTION**

Sammanfattningsvis visar resultatet från denna avhandling att för att transitionen att leva med diabetes ska innebära att personen mår bra är det är viktigt att kunna ta in andras erfarenheter samt att kunna lyssna och lita till kroppens signaler. Att våga möta det ”okända” innebar att få erfarenheter, vilka var viktiga för att också våga interagera med andra människor vilket personen kunna förstå mer om sig själv och sin sjukdom. Samtidigt var förmågan att kunna förstå kroppen som ett subjekt där kroppen, jaget och livet vävs samman och där diabetesen finns med är avgörande för en hälsosam transition. Att må bra innebär då att uppleva en balans mellan dessa delar. Genom att uppleva kroppen som ett subjekt blir också personen själv aktiv och ansvarstagande för sin hälsa till skillnad mot att uppleva kroppen som enbart ett objekt och bli beroende av andras kunskap vilket var förenat med osäkerhet.

Patientundervisning i grupp där personer med diabetes får dela sina erfarenheter verkar med resultat från denna studie kunna vara av stort värde, men först då personerna har förmågan att möta andras erfarenheter. Samtidigt visar resultaten att det är av yttersta vikt att vårdpersonalen kan möta en person med diabetes just där den personen är i sin transitionsprocess. Att lyssna till hur personen talar om sin kropp, som ett objekt eller subjekt blir då viktigt. Denna studie visar att duration av sjukdom inte är av avgörande betydelse för upplevelsen av vad det innebär att leva med diabetes. Livet efter tre år med sjukdomen kunde både upplevas som en tillvaro i balans men också som en daglig kamp.



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