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LIVING WITH DIABETES

-A LIFELONG LEARNING PROCESS

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Where is the Life we have lost in Living?

Where is the Wisdom we have lost in Knowledge?

Where is the Knowledge we have lost in Information?

T.S Eliot (1888-1965)

In Stories of the Human Spirit 'The Rock' from 1934



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Institutet**

LIVING WITH DIABETES

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THESIS FOR DOCTORAL DEGREE (Ph.D.)

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ABSTRACT

Living with diabetes, as a lifelong illness, is interlaced with learning and to face continual changes. However, the role of time in this learning process is not yet well understood. The overall aim of the thesis was to gain a deepened understanding of learning to live with diabetes for those recently diagnosed and over a three year period. The thesis, involving four studies where qualitative inductive content analysis (**I, III**) and phenomenological hermeneutical interpretation (**II, IV**) were used, has a lifeworld approach and a qualitative and longitudinal design. Thirteen persons, recently diagnosed with diabetes (type I or II), were interviewed on three different occasions over a three year period. All interviews focused on the experience of living with diabetes and situations where diabetes had to be taken into account. The aim of study **I** was to reach an understanding of how learning to live with diabetes is experienced in the first 2 months after diagnosis. The findings revealed to be taken over by a new reality, with a body that played a role in life with the health care service as a necessary partner. The aim of study **II** was to illuminate the meaning of learning to live with diabetes three years after being diagnosed. The findings revealed learning as making decisions through use of different sources of information and as solving the life-puzzle – a delicate balance to create a desired life. The aim of study **III** was to identify patterns in learning when living with diabetes, from recently being diagnosed, and over a 3-year period. In the findings five patterns were identified illuminating different learning processes emerging over time. A longer time living with diabetes did not per se mean increased satisfaction in living well with illness or increased confidence in understanding one's own needs. The aim of the **IV** study was to illuminate the meanings of trigger situations in learning to live with diabetes. The findings revealed trigger situations, such as being encumbered by vulnerability and temporality in unsustainable situations with an unpredictable body and a life involving new concerns for the future. The thesis conducted that learning was an informal and ongoing everyday process in life. Time living with diabetes meant both an increased mastery of a changed life situation, but also increased difficulties in achieving well-being and with a dependency on health care. Hence, health care interventions must adhere to the individual's needs and not be based on duration of illness. Understanding the body and the role of health care, as well as what facilitates and hampers learning, changed with time. It is therefore important that health care personnel illuminate the individual understanding and experiences of those living with diabetes as this was found to be important for the learning process as well as for their sense of well-being.

Keywords: diabetes, lifelong illness, learning process, transition, self-management, triggers, lifeworld philosophy, qualitative content analysis, phenomenological hermeneutic analysis

LIST OF SCIENTIFIC PAPERS

- I. Kneck, Å., Klang, B., & Fagerberg, I. (2011). Learning to live with illness: Experiences of persons with recent diagnoses of diabetes mellitus. *Scandinavian Journal of Caring Sciences*, 25(3), 558-566. doi: 10.1111/j.1471-6712.2010.00864.x
- II. Kneck, Å., Klang, B., & Fagerberg, I. (2012). Learning to live with diabetes: Integrating an illness or objectifying a disease. *Journal of Advanced Nursing*, 68(11), 2486-2495. doi:10.1111/j.1365-2648.2012.05947.x
- III. Kneck, Å., Fagerberg, I., Eriksson, L.E., & Lundman, B. (2014). Living with diabetes: Development of learning patterns over a 3-year period. *International Journal of Qualitative Studies on Health and Well-being*, 9(15), doi: 10.3402/qhw.v9.24375
- IV. Kneck, Å., Lundman, B., Eriksson, L.E., & Fagerberg, I. Encumbered by vulnerability and temporality: The meanings of trigger situations when learning to live with diabetes. (Submitted)

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List of concepts used in the thesis but not explored further

Person/Patient	In the thesis the terms ‘person living with diabetes’ or ‘the person with a lifelong illness’ are used. Exceptionally the term ‘patient’ is used and then refers to a group of ill persons in general in the context of health care.
Illness	In the present thesis a definition of illness, inspired by Kleinman (1978) is used. Illness refers to the personal, social and cultural context within a disease and how this is experienced and understood by the ill person. Illness further refers to the person’s own labelling, classifying and explanation of the experienced disease in such way that it can be personally and socially meaningful. Illness further refers to discontinuities and a devalued state of being, involving suffering with symptoms and losses. Illness also refers to a personal knowledge and consciousness of a disease.
Lifelong illness	A condition that is assumed to be long term or chronic related to a disease or to suffering.
Disease	A biological and/or physiological malfunction in body organ or systems.
Diabetes	Diabetes is a group of metabolic diseases characterized by the inability to sustain normal blood glucose levels referred to as hyperglycaemia and lack of metabolic control. Diabetes results from defects in insulin secretion, insulin action, or both.
Type I diabetes	Results from an autoimmune destruction of the β -cells of the pancreas usually leading to absolute lack of insulin. In order to survive persons with type I require substitution therapy with multiple injections of insulin daily.

Type II diabetes

A disorder of insulin action and insulin secretion resulting in a varying degree of insulin resistance and/or hyper or hypo insulin secretion. A healthy lifestyle, oral agents and/or insulin injections can constitute treatment for persons with type II.

HbA1c

Glycated haemoglobin test; provides information about the average levels of blood glucose for the last two-three months, the most established measurement for a longitudinal mean of metabolic control.

Hypoglycemia

Abnormally low glucose levels.

Secondary diabetes

Diabetes due to other causes, such as cystic fibrosis, drug or chemical treatment and different types of cancer of the liver or pancreas.

1 INTRODUCTION

Two situations have contributed to my interest in the research area of learning to live with diabetes as a lifelong illness from an everyday life perspective. Whilst I was working as a nurse on an evening shift a woman with unexplainable hypoglycemia was admitted to the ward. Even though she had had diabetes for several years, now in need of glucose infusion, this was one of the few occasions when she had to be admitted to hospital. However, the next morning, a Saturday, as soon as she saw me she told that she intended to go home, preferably immediately after breakfast. I phoned the doctor on duty and explained the patient's wish. After reading the patient's record the doctor said that the patient needed to stay on the ward as it was too risky to let her be at home in case a severe hypoglycemia attack would recur. I found this reasonable. The patient did not agree with the decision as she thought staying on the ward would probably result in hyperglycemia as the food and activities were not in line with how she wished or was used to. She continued saying that earlier she had had similar severe hypoglycemia attacks, but then she had managed on her own and that this was just the way her diabetes worked. I found her explanation reasonable. In the subsequent dialogue between the doctor and the patient it became clear that they both liked to feel secure and in control, but that the ways of achieving this were totally different. The other situation occurred in a discussion during a course on adult learning. Adult learning was described as life-oriented, informal and based on one's own interests and personal goals, and described as individually chosen and enjoyable. During the session I thought of these assumptions related to learning for adults who had received a diagnosis of a lifelong illness, such as diabetes. The two situations triggered questions such as; How is learning characterized in relation to living with a lifelong illness? Is learning enjoyable? Is it voluntary and individually chosen? When does a person with lifelong illness learn? What triggers learning and how come they sometimes do not seem to learn? These questions formed the platform for a desire to understand more, resulting in this thesis.

2 BACKGROUND

To live with diabetes is a reality for many in Sweden as well as globally. In Sweden approximately 365,000 persons have been diagnosed with one type of the disease. A diagnosis of diabetes often involves new needs and demands. In the Background section the concepts of ‘living with diabetes’, ‘transition’, ‘learning’, ‘self-management’, ‘health and well-being’ and ‘diabetes care’ are illuminated in relation to these needs and demands. As living with diabetes shares similarities with living with other lifelong illnesses literature both related to lifelong illness in general and specific to diabetes has been referred to.

2.1 LIVING WITH DIABETES

Living with diabetes refers to the person’s own experiences and understanding, and is described as an illness perspective, while a disease perspective focuses on objective symptoms, test results and treatment from a biomedical standpoint (Toombs, 1993; Zoffmann, Harder & Kirkevold, 2008). Toombs (1993) describes illness experience involving lived knowledge and lived understandings gained from daily life, further referred to as “the stories of the ill” (Frank, 1998, p.197). Zoffman et al. (2008) describe persons living with diabetes as having a life-oriented perspective, while health care personnel have a disease-oriented perspective. However, both an illness as well as a disease perspective have been found to be of importance for the person with a lifelong illness. Edvall, Danielson and Öhrn (2010) found that objective controls gave important insight into health for persons with diabetes, while how one felt was of greater importance than objective measurement in Moser, van der Bruggen, Widdershoven and Spreuwenberg (2008b) study.

Being diagnosed with diabetes, or living with the risk of developing a lifelong illness, has been described as a life – altering event (Kralik, 2002), alternatively being overwhelmed (Paterson, 2001) or impossible to continue living as if nothing had happened (Anderson, Ekman, Lindblad & Friberg, 2008). Living with a lifelong illness often involves facing many changes; a changed body as well as a changed life, including changes in roles, responsibilities and social relationships (Charmaz, 1983; Kralik, Koch, Price & Howard, 2004; Michael, 1996; Paterson, Thorne & Dewis, 1998). To experience suffering, grief, impaired

quality of life and a negative impact on physical health (Charmaz, 1983; Nicolucci et al., 2013), as well as worries about future complications (Skovlund & Peyrot, 2005), are other aspects of living with diabetes. Living with a lifelong illness is further described as experiencing losses in relation to one's sense of self, personal identity and loss of social identity and role (Aujulat, Luminet & Deccache, 2007; Kralik et al., 2004). Toombs (1993) uses the expression a fundamental loss of wholeness and Kralik (2002) loss of what earlier was taken for granted, and Nicolucci et al. (2013) describe it as finding it impossible to live a normal life. Kralik et al. (2004) found that living with lifelong illness involved the need to bring order into daily life with solutions that fitted with one's own life situation. However, living with diabetes was also found to be a positive experience, involving feeling better and experiencing having a more healthy lifestyle than previously (Koch, Kralik & Taylor, 2000). Living with a lifelong illness can also provide an opportunity to learn more about oneself (Berglund, 2014).

A need for a changed identity is described when new demands to take care of oneself, related to physical needs as well as social, spiritual and cultural aspects, are experienced (Kralik et al., 2005; Person, Winkvist & Mogren, 2010). Kralik et al. (2004) portray coming to terms with lifelong illness as more than doing instead a sense of being and becoming illuminating an identity reformation. Asbring (2001) describes the need for reflection as essential for coming to terms with a new identity, also described as self-reformulation (Mayan, Morse & Eldershaw, 2006) or a need for a reconciled self (Aujulat, Marcolongo, Bonadiman & Deccache, 2008). Living with diabetes and other lifelong illnesses are further described as a constant and complex balancing act, between what one wants to do and what one think one should do or what is socially acceptable (Andersson et al., 2008; Ingadottir & Halldorsdottir, 2008; Lin, Anderson, Hagerty & Lee, 2008; Whittemore & Roy, 2002), as an inner negotiation between different needs, e.g. social and medical (Auduly, Norbergh, Asplund & Hörnsten, 2009). Learning to strive for balance is described by Berglund (2014) as an aim for living well with lifelong illness, further described as a balance between holding on and letting go of control (Aujulat et al., 2008). To experience a changed self, losses, as well as a need to manage an altered life situation illuminates a transition experience.

2.1.1 Transition - living with change

Facing change is one part of living and constitutes a transition experience. A 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). Van Genneep (1960/2004) describes life itself as a series of transitions with passages that one needs to go through such as ‘rites of separation’, ‘transition rites’ and ‘rites of incorporation’. Bridges (2009) describes transition as a phase of separation and loss, as ‘ending, losing, letting go’ followed by the phase of ‘the neutral zone’ and finally ‘the new beginning’. How persons relate to and manage transition in general has been referred to through van Genneep’s (1960/2004) and Bridges’ (2009) theories, who conclude that the process involves going through different distinct phases in chronological order. However, in relation to living with diabetes and other lifelong illnesses different kinds of transition have been addressed. A linear process with more or less chronological phases has been described with an initial phase, an experimental phase and an integration phase (cf. Paterson & Thorne, 2000; Price, 1993). Further illustrated by Hernandez (1995, 1996) describing a three-phase process; ‘having diabetes’, ‘the turning point’ and ‘the science of one’ as diabetes gradually becomes part of the person’s self. Others found that a changing life and body meant new challenges and needs related to the transition, resulting in a fluctuating process (cf. Kralik, 2002; Whittemore & Dixon, 2008) as well as a constant shifting between different perspectives and interests. A shifting process is described as illness or wellness in the foreground (Paterson, 2001) and Whittemore and Dixon (2008) describe shifts between ‘living a life’ and ‘living an illness’. Turning points, described as important life events (Meleis, Sawyer, Im, Hilfinger Messias & Schumacher, 2000) also influence transition with a new awareness and the meanings of the transition contributing to change within the person (King et al., 2003). Turning points are further described as making persons with lifelong illness more aware of the severity of the illness, as well as becoming more engaged in self-management (Hörnsten, Jutterström, Audulv & Lundman, 2011; Jutterström, Isaksson, Sandström & Hörnsten, 2012b). The amount of available resources together with the intensity of barriers have been found to influence the transition, both inhibiting and facilitating reaching the integration phase (Whittemore & Dixon, 2008). Mastery is described as a desired outcome when living with lifelong illness, as well as when experiencing a health – illness transition.

Mastery, when experiencing control in one's life involving a sense of new identity is related to experiencing health (Meleis et al., 2000). Mastery is also referred to as being empowered, being capable of managing a changed health situation and being able to make independent and autonomous choices in everyday life settings (Funnell & Andersson, 2003; Meleis et al., 2000; Tang, Funnell, Brown & Kurlander, 2010). Examples of contrast to a healthy transition are the experience of powerlessness, suffering and dependency (Meleis et al., 2000). Dependency is to experience limited freedom to choose, with autonomy requiring valuable options to choose from (Sandman, Granger, Ekman & Munthe, 2012). However, living with diabetes and other lifelong illnesses has also been described as experiencing powerlessness and too few resources to perform self-management in daily life (Audulv, Asplund & Norbergh, 2010; Aujoulat et al., 2007). Wikblad, Smide and Leksell (2014) address the experience of the considerable burden of diabetes associated with a negative attitude towards the illness and its management.

Time and timespan are considered to be important in transition, since coming to terms with a changed life situation takes time (Kralik, Visentin & van Loon, 2006; Meleis et al., 2000). Time living with a lifelong illness has in some studies been shown to contribute increased opportunities for managing illness related needs, described in terms of being more mature in handling the demands of illness (e.g. Chapple & Rogers, 2001; Kay, Davis, Gamsu & Jarman, 2009). Persson et al. (2010) found that with time it became gradually easier to live with gestational diabetes, described as moving from stunned to gradual balance. However, Riegel, Jaarsma and Strömberg (2012) found persons with lifelong illness years after being diagnosed having difficulty managing needs in relation to the illness. Time living with diabetes can also mean new needs in relation to changed medical treatment. For example, Esposito, Chiodini, Bellastella, Mariorino and Giugliano (2012) stress that the progressive nature of type II diabetes with increasing blood glucose levels over time for many persons means a shift from oral agents to insulin injections.

Today, despite the extensive research conducted on living with diabetes and other lifelong illnesses, longitudinal studies are rare in scientific literature and it is not well understood how time contributes to the process of living with a lifelong illness (Kralik et al., 2006; Rasmussen, Ward, Jenkins, King & Dunning,

2011). However, experience of time when living with lifelong illness has been found to influence the person's life as well as how he/she seeks health care (Charmaz, 1983; Hajdarević, 2012). A changed insight into time was found in the Hood, Huber, Gustaffson, Scambler and Asimakopoulou (2009) study when persons who lived with diabetes for many years wanted to advise persons with newly diagnosed diabetes to take the illness more seriously than they themselves had done. Knowing the consequences of one's choices when living with a lifelong illness is difficult, described by Berglund (2014) as realizing too late when experiencing a negative development of the disease. Understanding the importance of time for a transition experience is important for knowing when health care interventions are suitable, described as 'timing' (Chapple & Rogers, 2001). How time for everyday life experiences contributes towards mastering one's own care as well as experiencing autonomy when living with diabetes is not yet well understood, and needs to be further explored. Transition is also related to learning, gaining the knowledge and skills needed to manage the new needs and demands involved in the transition (Kralik et al., 2004; Meleis et al., 2000).

2.2 LEARNING

Learning is described as when a person develops and grows as a result of responding to a situation with which he/she has not been previously familiar. Learning means to integrate new understanding as well as to understand the world differently (Jarvis, Holford & Griffin, 2003). Inspired by the philosophy of Merleau-Ponty, Talero (2006) described learning as a remarkable part of human life with it being difficult to draw a firm line between being alive and learning. Jacob (1994) describes living as a process of becoming rather than a state of being. Dahlberg, Todres and Galvin (2009) describe living as existing in movement, an ongoing response to the circumstances experienced, assuming openness as well as engagement, but also involving limitations and vulnerability. Experiences are the foundation of and stimulus for learning, described as 'the triggers'. Experiencing a trigger is further described as making the person more active and engaged in her/his own learning (Knowles, Holton & Swanson, 2005). However, Jarvis et al. (2003) state several other alternatives as response

to experiences where non-learning includes presumptions, non-considerations and rejection as the typical way of responding to everyday experiences. Learning is described in relation to change, e.g. in knowledge, skills or understanding as the correction of the imbalance between intentions and what actually happens. Learning can both be understood as a product or an outcome as well as a process occurring in everyday life influenced by earlier experiences. Learning is also context-driven with social interaction and the need for socialization, such as the internalization of values, beliefs and norms of a particular society (Illeris, 2005; Jarvis et al., 2003). Lifelong learning is described as the vehicle for persons towards the fulfilment of individual life goals, addressed as developing human capital and promoting success at a societal level (Tight, 1998). Lifelong learning emphasizes the learner's autonomy and the focus on the learner's needs and interests, as well as being mostly self-directed and life-centered (Knowles et al., 2005). However, studies into learning related to diabetes primarily focus on learning as a planned activity with outcomes predefined by health care staff or researchers (Duncan et al., 2011; Tshiananga et al., 2012). Jarvis et al. (2003) stressed that most formal education has predefined behaviouristic goals that are to be achieved. Most diabetes research related to learning focuses on self-management as one aspect of learning.

2.2.1 Self-management – a part of learning when living with lifelong illness

Persons living with diabetes and other lifelong illnesses are expected to be active and responsible for the daily care of their illness, involving any new demands that need to be managed (Balfe, 2009; Rasmussen, O'Connell, Dunning & Cox, 2007) often referred to as self-management (Funnell & Andersson, 2003; Paterson & Sloan, 1994; Tang et al., 2010). Self-management when living with diabetes refers to food habits and healthy eating, physical activity, glucose monitoring, medical treatment, insulin injection and recognition and management of hypo and hyperglycemia (Inzucchi et al., 2012; McEwen, Baird, Pasvogel & Gallegos, 2007). Tshiananga et al. (2012) raise the increased requirement for the ill person to independently perform self-management as a result of an overburdened health care system, the escalating cost of diabetes care, and limited human resources. Moser, van der Bruggen and Widdershoven (2006)

address self-management as autonomy and an opportunity for development of the person's own competency, as well as for shaping one's own life, in line with the definition of learning (Jarvis et al., 2003).

Worldwide a range of diabetes self-management education (DSME) exists which aims to support persons living with diabetes. Different approaches are used aiming at specific outcomes, e.g. increasing knowledge and skills, in relation to self-assessment, or preventing complications and lifestyle adjustments.

Independence from health care, lower health care costs and providing care aligned with recommended guidelines are also addressed (Duncan et al., 2011; Tshiananga et al., 2012). In a meta-analysis Tshiananga et al. (2012) found that change in metabolic control (HbA1c) was the predefined outcome for most DSME programmes. However, others address change in behaviour as a more sensible outcome of DSME than glycaemic control, since a change in one's ability to manage one's life is considered to constitute learning (Ellis et al., 2004; Walker, 1999). To be fully informed but to then choose not to change one's behaviour is another aspect of learning (Walker, 1999). DSME programmes and care based on patients' own experiences and understanding have been found to enhance knowledge of personal health, improve self-care ability, create greater satisfaction with care, have positive and lasting effects on metabolic control and increase quality of life (Coulter & Ellins, 2006; Hörnsten, Stenlund, Lundman & Sandström, 2008a). However, interventions from health care aiming to increase a person's ability to perform self-management are often short-term focused, lasting from a week to a couple of months, with outcomes measured shortly after the intervention. More often than not, changes related to interventions in DSME programmes are not maintained over time (Tshiananga et al., 2012) with few exceptions (cf. Hörnsten et al., 2008a).

The relationship between self-management and learning are not often addressed in DSME programmes since most studies are not aligned with the principles of adult learning and theoretical models guiding intervention (Williams & Pace, 2009). Berglund and Källerwald (2012) stress the learning process as a missing element in studies on experiences of living with lifelong illnesses. In summary, learning can be described as a way of existence as well as a predefined activity decided by others. In diabetes research the latter definition of learning has been the focus. Learning interlaced with experience is subjective and lifelong. A

lifelong learning illuminates a never-ending process involving tension when faced with problems and influenced by personal expectations, needs, ideas and values raised over time (cf. Jarvis et al., 2003; Knowles et al., 2005; Mezirow, 1998). Self-management is central when living with diabetes and several interventions are carried out to support self-management even if changes in self-management are seldom maintained. The relationship between self-management and learning is seldom addressed (cf. Berglund, 2014). However, how one lives and learns when performing self-management is of importance for one's health.

2.3 HEALTH AND WELL-BEING

Health and illness are dimensions of being human. In this thesis health and well-being are understood to be interlaced concepts, with health as the overall concept but with well-being as essential for experiencing health. Health and well-being refer to the physical condition of the body as well as the experience of the rhythm of life, a process or movement that can be broken by an illness experience. Experience of health involves being able to live and carry on one's life projects, large or small (Dahlberg et al., 2009). Health and well-being are also related to an energized feeling of vitality allowing an un-preoccupied and vital movement into a desired future. Well-being refers to a feeling of acceptance and being at peace with one's life situation. To feel able to engage with the world as well as with others is important in order to feel connected, and is important for a healthy transition (Meleis et al., 2000), further described as aspects of health (Dahlberg et al., 2009).

In caring science, interpretation, experience and one's own understanding are related to both health and illness, and health is described as holistic and subjective (Dahlberg et al., 2009). Learning is often implicitly interwoven into the definitions of health. Health as well as learning is understood to involve changing processes within the person involving freedom and power (cf. Freire, 1993; Meleis et al., 2000) aiming to promote personal and social growth and achieve change, in a movement of 'becoming' (cf. Eriksson, 2002; Jarvis et al., 2003; Meleis et al., 2000). Meleis et al. (2000) address concepts such as awareness, engagement, change and differences influencing a transition experience and the importance for experience of health and suffering, in line with the core concepts of learning (Jarvis et al., 2003). According to Peplau

(1988) being ill is a learning experience described as an ‘educative process’. Health and learning are described as ‘active becoming’ as well as ‘the will to find meaning’. To strive towards a realization of one’s own potential, as a never-ending process of reconciliation of wholeness is interlaced with health (Eriksson, 2002) and with learning (Jarvis et al., 2003).

Experiencing health despite a lifelong illness is related to illness integration, associated with feeling responsible and independent in one’s decision-making (cf. Audulv et al., 2010; Hernandez, 1995; Thorne, Paterson & Russel, 2003). This is further addressed as taking ownership of one’s illness, focusing on living – though not at the expense of the demands of one’s illness (Hernandez, 1995; Hörnsten et al., 2011; Paterson, 2001; Whittmore, 2005; Whittmore & Dixon, 2008) together with achieving satisfactory glycemic control among persons with diabetes (Veg, 2006). Being active and engaged in one’s own care has been found to be essential for well-being when living with diabetes and other lifelong illnesses (van Dam, van der Horst, van der Borne, Ryckman & Crebolder, 2003; Whittmore & Dixon, 2008) as well as essential for learning (Knowles et al., 2005). Berglund (2014) states that learning to live with a lifelong illness requires an active effort to make the illness visible in the person’s life. Persons with diabetes who were active in relation to their self-care (‘disease managers’) expressed a higher level of control, had better metabolic control and were more independent from health care than those who merely complied with care recommendations (Veg, 2006). However, personal involvement in and management of change in one’s own care over time is not yet well understood. In contrast it is well known that impaired metabolic control over time increases the risk of complications. An increased HbA1c level is strongly correlated to the development of complications, such as kidney complications, cardiovascular diseases and foot ulcers (American Diabetes Association [ADA], 2012; Yang, Chasenese, Sereika & Burke, 2009). Depression and experiencing diabetes distress¹ is also related to an increased HbA1c levels (Norris, Lau, Smith, Schmid & Engelgau, 2002; Peyrot et al., 2005; Snoek et al., 2011; Sorkin et al., 2011).

¹diabetes distress, defined as a person with diabetes concerns and worries about disease management, support, emotional burden, and access to care (Fisher, Glasgow, Mullan, Skaff & Polonsky, 2008).

Complications, already developed when diagnosed with diabetes are raised as a common problem in type II diabetes (Looker et al., 2012; Simmons & Feldman, 2002), which in turn is related to a high number of persons with undiagnosed diabetes, even though prevention and screening have improved over the last six years (Garrofé, Björnberg & Phang, 2014). It is common that persons with diabetes also have one or more other lifelong illnesses, described as an ‘epidemiology of multimorbidity’ (Barnett et al., 2012). There is a large percentage of persons with diabetes in Sweden as well as internationally who do not achieve satisfactory metabolic control (International Diabetes Federation [IDF], 2014; Nesbeth, Orskov & Rosenthal, 2009; Oftedal, Karlsen & Bru, 2010). For example, in Swedish primary care 51 percent of persons with type II diabetes did not reach set goals for metabolic control. These results are in line with the results for the US where about half of the population with diabetes have HbA1c levels above ADA guidelines for metabolic control (Dodd, et al., 2009).

In summary it can be concluded that persons living with diabetes have an increased risk of impaired health and well-being. In order to decrease this risk health care intervention are carried out.

2.4 DIABETES CARE

A person-centred approach with the patients’ individual needs, values and preferences as the focus should guides decision-making within the Swedish health care system (Docteur & Coulter, 2012). Sweden, followed by the Netherlands and Denmark, has been ranked number one for diabetes care in Europe (Garrofé, et al., 2014). This is the case despite the fact that national targets for smoking cessation, increased physical activity and HbA1c levels have not been achieved (National Board of Health and Welfare, 2012). Systematic reporting of important data is given as an explanation for good quality care and for improvement of care (Garrofé, et al., 2014) with diabetes team members being required to register objective measurement statistics to the National Diabetes Register (Gudbjörnsdóttir, Cederholm, Nilsson & Eliasson, 2003; Nationella Diabetesregistret [NDR], 2013). In Sweden person-centred group education is considered to be important and is given high priority (National Board of Health and Welfare, 2012; Statens beredning för medicinsk utvärdering

[SBU], 2009). At the same time predetermined targets for certain patient groups are defined. Two such targets are to reduce the proportion of persons with an HbA1c of ≥ 73 mmol / mol and to increase the proportion of those with diabetes who regularly exercise at least three times per week (National Board of Health and Welfare, 2012).

It is a basic principle in person-centred care that power, responsibility and control are shared between the patient and the caregiver. Mutual agreement and shared decision-making in partnership are described as essential for 'centredness' (Ekman et al., 2011; Hughes, Bamford & May, 2008; McCormack, Dewing & McCance, 2011; McCormack & McCance, 2006). Person-centred interventions have been shown to help professionals gain insight into patients' own experiences and understanding, which is important for identifying problems and for shared decision-making (Suhonen, Välimäki & Leino-Kilpi, 2008; Zoffman et al., 2008). However, within Swedish health care it often happens that patients' individual needs, values and preferences are not sufficiently taken into consideration (Docteur & Coulter, 2012). Research shows that a pedagogical approach based on formalized procedures rather than one that is problem-oriented is often performed. Boström, Hörnsten, Lundman, Stenlund and Isaksson (2013) found that a person-centred approach with the traditional roles of the diabetes specialist nurse (DSN) as the one having the knowledge and providing information and the patient as the one passively receiving the information needed to be changed. Checklists were frequently used and goals for patient care were in most cases determined without patient involvement (Björk Brämberg, Dahlborg-Lyckhage & Määttä, 2012; Thors Adolfsson, Smide, Rosenblad & Wikblad, 2009). Lack of involvement in one's own care is described as to be a problem as it could imply a negative effect on the patient's perceived quality of care, poorer health outcomes and unnecessary costs for health care and society at large (Docteur & Coulter, 2012). The lack of patient participation and shared decision-making further illuminated an approach where knowledge was accepted as true, objective and general, and transmitted as just information. At the same time general information had been found to be hard to understand as well as to put into practice when it was not considered relevant to one's own life situation (cf. Berglund & Källerwald, 2012; Hörnsten, Lundman, Selstam & Sandström, 2005).

DSME programmes have a wide range of different goals, e.g. goals on an individual bio-physical level, such as optimized metabolic control, as well as those at society level, such as reduction of the number of hospital stays. Other holistic individual goals have been described, such as helping a person achieve a balance between the demands of illness and living a meaningful life (cf. Moser et al., 2008b; Norris, Engelgau & Narayan, 2001; Norris et al., 2002). Different goals in health care are further described as a variety of interest in health care (Mead & Bower, 2002). Different interests and values in health promotion are raised by Jacob (1994) illuminating the need to either respect the person's freedom and right to choose even if it means an extra burden and cost for the person and/or society, or to consider that the person's right and freedom to choose can be sacrificed for the greater benefit for the majority of society. Different interests and guidelines are problematic for health care personnel as well as for persons living with diabetes. This has been illuminated by Hörnsten, Lundman, Almqvist and Sandström (2008b) when the diabetes specialist nurse (DNS) experiences daily situations where conflicting interests and goals will arise. Hernandez (1995) described a paradox for persons living with diabetes where whilst encouraged to take responsibility for their own self-management they were also expected to follow health care advice. Therefore to better understand how nurses can perform person-centred care to support learning for persons living with diabetes knowledge of the person's everyday life experiences is needed.

2.5 THEORETICAL FRAMEWORK

2.5.1 The lifeworld

The lifeworld is a world of experiences where we live our everyday life and understanding and meanings are implicit, taken for granted. The concept of the lifeworld has its roots in phenomenology as well as hermeneutics and is a world of subjectivity based on the assumption that humans cannot experience something without interpretation (Dahlberg, Dahlberg & Nyström, 2008). Merleau-Ponty (1945/2002) described the lifeworld as a world of perception, an everyday world where we act and respond naturally. The lifeworld is also a world of interaction and Merleau-Ponty (1945/2002) describes the body as the vehicle for our being in the world, our connection in the world. With the body we interact with the world which is a world we cannot be separated from. Merleau-Ponty (1945/2002) also describes the 'lived body' as an intertwining of body, self and the world that must be understood as a whole and which influences and is influenced by others. The physical body that we can observe is just a visible side of something much larger, described as the subjective body, which is perceptual, spatial and interpersonal (Talero, 2006). This is further illuminated by Bullington (2009) who describes an objective body that we have and a subjective body which we are. From a lifeworld perspective to be human is to be in a process which never finishes, one of constant development (Dahlberg et al., 2008). When we encounter the world we carry a personal frame of reference from our past experiences and values where culture and history are included (Merleau-Ponty, 1945/2002). At the same time encountering the world is to experience an infinite openness to the future, as a broader presence, described by Merleau-Ponty (1945/2002) as a storm on the horizon moving to meet the person. The lifeworld consists of fields of presence that have already slid by but also fields that can still be experienced. A situation is to be situated in time as well as to experience a movement of temporality. This movement of temporality is described in terms of a process. Ekebergh (2009) describes learning and caring as two parallel processes within the lifeworld. The process of learning is understood to be interlaced with and of importance for the process of health.

From a lifeworld perspective, learning is based on one's own earlier experiences and understanding, making learning an individual experience even if others

influence the process. According to Ekebergh (2007) the lifeworld is the platform for learning and through reflection the learning process starts and is continuously ongoing. Learning is further understood as the fundamental form of existence, as the body-subject is a learning subject as well as learning being essential for experiencing freedom (Talero, 2006). However, human existence is also habitual involving an automatic performance, enabling us to act in a meaningful manner, which is important for being able to focus on our life project. This is described by Talero (2006) as work behind the scenes operating in an invisible medium. Bullington (2009) describes structures of our being as both regimented as well as spontaneous, meaning a flow of change in every situation. Change according to Saldaña (2003) refers to both a 'then' and a 'now' illuminating the past as important for the present situation. Learning can both be objective and measured as well as subjective and experienced (Jarvis et al., 2003). However, with a lifeworld perspective, learning always has to be subjective. Learning being interlaced with experience, interpretation and meaning occurs in everyday life situations as a unique response to meeting changes and being changed, but we cannot predict how.

Learning in this present thesis is the main process, and is important for and interlaced with the process of health. The lifeworld is essential for learning as well as health and the lifeworld is essential for the process of living. The person is further understood to be situated in the lifeworld through the lived body. Interlaced with the processes of learning, health and living are other processes such as self-management and transition. Part of the process of health is well-being, but well-being together with mastery, empowerment, autonomy and fulfilment of life goals are also desired outcomes, all influencing and being influenced by the processes of learning, health and living.

3 RATIONALE

Living with an illness such as diabetes is a lifelong process interlaced with other lifelong processes such as learning, transition and self-management, all of which are important for the process of health. In health care one goal for persons living with diabetes is to attain mastery in managing a changed health situation with the ability to be independent in decision-making and to experience control, further described as dimensions of health. At the same time it is known that living with diabetes involves needs and demands that are changing with time as life itself changes with the continual interaction between the person and different situations. Time and timing are important aspects of the processes of living, learning and health, as well as for health care intervention to be successful. The lack of longitudinal studies is problematic and the extending process over time of learning to live with diabetes is therefore not yet well understood. A deepened understanding of learning over different time spans could provide knowledge of the process of learning to live with diabetes, and would be important for understanding how health can be experienced and supported despite a lifelong illness. A lifeworld perspective can provide ‘lived knowledge’ of the process of learning to live with diabetes from an everyday learning perspective. In line with a person-centred approach, knowledge of the process of learning to live with diabetes based on everyday life experiences can be important for the development of health care intervention.

4 AIMS

The overall aim of the thesis was to gain a deepened understanding of learning to live with diabetes after being recently diagnosed and over a three-year period.

The aims of the four studies were the following:

I: To reach an understanding of how learning to live with diabetes is experienced in the first 2 months after diagnosis.

II: To illuminate the meaning of learning to live with diabetes three years after being diagnosed.

III: To identify patterns in learning when living with diabetes, from recently being diagnosed, and over a 3-year period.

IV: To illuminate the meanings of trigger situations in learning to live with diabetes.

5 DESIGN AND METHODS

The thesis has a qualitative and longitudinal design and comprises four studies (I-IV). An overview of the studies is provided in Table 1. Thirteen persons all with a recent diagnosis of diabetes were interviewed on three different occasions over a three-year period with the aim of reaching a deepened understanding of the learning process when living with diabetes. Learning is related to change and according to Saldaña (2003) at least two different reference points, a 'then' and a 'now', are needed in order to enable change to be analyzed. For the present thesis a longitudinal design was therefore considered important for achieving the overall aim. An assumption in longitudinal studies, or 'time-series analysis', is that time and change are central. A longitudinal study, however, provides no guarantee that changes will be found, but only provides the possibility. Saldaña (2003) describes longitudinal studies in terms of life-course research, e.g. in relation to human actions and pathways. Longitudinal studies provide an opportunity to describe changes at different time points as a way of identifying patterns and human development and to better understand how people think, act and feel.

The design of the studies (I-III) was based on Saldaña's (2003) recommendation to divide longitudinal qualitative data into time pools as this make changes more apparent and a large amount of data more manageable. In the first two studies (I-II) an understanding of learning to live with diabetes at two different reference points was formed, within the first two months after the diagnosis (I) and after three years (II). Based on the findings from study II, it was considered of interest to identify and describe different learning patterns, which then became the aim for study III. Saldaña (2003) describes situations involving contradictions with a potential for learning, and thus illuminating the meanings of trigger situations in learning to live with diabetes, which became the focus for study IV.

Table 1 Overview of the studies

<i>Study</i>	<i>Aim</i>	<i>Method</i>	<i>Data</i>	<i>Findings</i>
I	To reach an understanding of how learning to live with diabetes is experienced in the first 2 months after diagnosis	Qualitative inductive content analysis on a group level based on interviews from the first interview occasion.	Interview occasion I	<u>Themes:</u> Taken over by a new reality The body plays a role in life Different ways of learning The health care service as a necessary partner
II	To illuminate the meaning of 'learning to live with diabetes' three years after being diagnosed.	Phenomenological hermeneutic interpretation of data from the third interview occasion.	Interview occasion III	<u>Themes:</u> Learning to make decisions by using different sources of information Solving the life-puzzle – a delicate balance to create a desired life
III	To identify patterns in learning when living with diabetes, from recently being diagnosed, and over a 3-year period.	Qualitative inductive content analysis on an individual as well as a group level based on data from all three interview occasions.	Interview occasions I,II,III	<u>Patterns:</u> To find the balance, gradually letting oneself live Active searching for knowledge to gain control Despite obstacles, having the strength to do what is important The hazards dominate when it becomes increasingly difficult to attain an acceptable blood glucose level With knowledge and motivation adapt to minor changes in daily life
IV	To illuminate the meanings of trigger situations in learning to live with diabetes.	Phenomenological hermeneutic interpretation of selected data from the three interview occasions.	Interview occasions I,II,III	<u>Main theme:</u> Encumbered by vulnerability and temporality <u>Themes:</u> Unsustainable situations An unpredictable body and life Dependability on oneself and others The unforeseeable demands of the future

5.1 PARTICIPANTS AND SETTINGS

The participants were recruited from an endocrinological ward at a Swedish University Hospital. Potential participants were identified from an enrolment list of patients treated on the ward. The inclusion criteria for the participants were; recently diagnosed with diabetes, over 18 years of age and Swedish-speaking. Potential participants were informed about the study by mail approximately one week after being discharged from the hospital. A few days later, they were contacted by telephone and could ask questions before deciding whether or not they wanted to participate in the study. Before each new interview, participants received both written and oral information and gave their verbal informed consent. France, Bendelow and Williams (2000) consider informed consent a process especially important in a longitudinal study.

The participants were recruited consecutively at first and later on selectively. A selective sampling became necessary as the first consecutive recruitment mainly resulted in men with similar conditions. The selective sampling was employed to reach variation as regards diagnosis, gender, age and social and working conditions. In total 16 persons were asked to participate of whom three women declined, resulting in 13 participants; 4 women and 9 men, with different living conditions (3 living alone, 10 living with a partner) and working conditions (11 working, 2 not working) and types of diabetes (5 with type I and 8 with type II) as well as a variation in ages between 26 and 65 (median 43) years. (see Table 2 for further clinical characteristics of the participants). Selected sampling or purposive sampling, aims to attain a variation in relation to the phenomena of interest, described as 'phenomenal variation' (Sandelowski, 1995,1999). According to Patton (2002) participants with the best knowledge or appropriate experience of the research topic are sought out. In line with the recommendation of the National Board of Health and Welfare (2012) the participants, similar to other persons newly diagnosed with diabetes at the current hospital, have been offered a course in diabetes self-management.

Table 2 Clinical characteristics of the participants

(The number I, II or III in the table refers to the interview occasion)

Partici pant	Type of diabetes	Metabolic control I	Metabolic control II	Metabolic control III	Medical treatment I	Medical treatment II	Medical treatment III
P1	Type 2	within reference values	within reference values	within reference values	tablets + insulin	tablets + insulin	tablets + insulin
P2	Type 2	over reference values	slightly elevated	slightly elevated	tablets + insulin	tablets + insulin	tablets + insulin
P3	Type 1	strong fluctuations	elevated values	within reference values	insulin	insulin	insulin
P4	Type 1	within reference values	elevated values	within reference values	insulin	insulin	insulin
P5	Type 2	within reference values	within reference values	strongly elevated values	tablets + insulin	tablets + insulin	tablets + insulin
P6	Type 2	within reference values	within reference values	within reference values	tablets + insulin	tablets + insulin	tablets + insulin
P7	Secondary due to other condition	within reference values	within reference values	within reference values	insulin	insulin	tablets + insulin
P8	Type 2	elevated values	elevated values	strongly elevated values	tablets + insulin	tablets + insulin	tablets + insulin
P9	Type 2	slightly elevated	within reference values	elevated values	tablets + insulin	tablets	tablets
P10	Type 1	within reference values	elevated values	within reference values	insulin	insulin	insulin
P11	Type 2	within reference values	slightly elevated values	within reference values	insulin	insulin	insulin
P12	Type 2	elevated values	within reference values	within reference values	tablets + insulin	tablets + insulin	tablets + insulin
P13	Type 1	elevated values	within reference values	within reference values	insulin	insulin	insulin

5.2 DATA COLLECTION

Participants were interviewed between the first and second month, after one year and after three years after being diagnosed with diabetes. All interviews started with the same the initial question ‘How do you experience living with diabetes?’ Later on in the interview the participants were asked to narrate situations where they had had to take their diabetes into account. In order to reach a deeper understanding, probing questions, such as “‘Could you tell me more about that?’” “‘What did you do?, ’”What did you think? or “‘What did you feel?’” were asked to stimulate the participant to narrate more about an experience or a particular situation. This procedure was based on the assumption that learning involves thoughts, experiences, acts and feelings (cf. Berglund, 2014). The interviews were audio-taped and transcribed verbatim. All participants completed the study and the data collection resulted in 39 interviews and approximately 300 pages of transcribed text (see Table 1 for how data was used for different studies).

5.2 ANALYSIS

Data consisted of transcribed interview texts from the interviews for all four studies (I-IV). However, different interview texts as well as different qualitative inductive methods were used (Table 1). In common for all qualitative inductive methods there is a need to go back and forth in the process for analyzing and understanding data (Pyett, 2003), and regardless of method there is always some degree of interpretation when addressing a text (Graneheim & Lundman, 2004).

5.2.1 Lifeworld research

Ontology refers to being in the world and the structure of reality as to the meanings that constitute a certain phenomenon, in the present thesis the phenomena of ‘learning to live with diabetes’ (cf. Dahlberg et al., 2008). Ontological assumptions for the present thesis are presented in the Background and in the Theoretical Framework sections. An assumption in the present thesis is that knowledge is based on subjective experiences, experienced through the subjective body, the ‘lived body’, as lived experience. Ricouer (1998) emphasizes that lived experience is always private but the meaning of it can be communicated. Lifeworld research aims to try to understand and describe the lived experience from interpretation, which can be on different levels of

abstraction (cf. Dahlberg et al., 2008). This is described by Ricoeur (1976) as an opportunity to reach a deeper understanding of what it means to live in the world. Interactions are the engagement between the person and the world and these relationships are experienced in the everyday world (Dahlberg et al., 2008). Interactions are the foundation for creating understanding and have been an epistemological underpinning for the present thesis (cf. Powers & Knapp, 1995). Interviews are interactions between the researcher and the participants, both creating a communication, a shared speech context, that can be transcribed into text. Since all texts have multiple meanings an interaction between the researcher and the text develops during the analysis process. The interaction is influenced by the researcher's earlier experiences and qualification but also requires bracketing (Dahlberg et al., 2008; Patton, 2002). Bracketing is aiming not to be too quick to understand or judge a certain phenomenon through awareness of the context from one's own previous experience (Drew, 2001; Fleming, Gaidys & Robb, 2003). At the same time earlier experiences are necessary in order to interpret and understand something new or something in a different way (Fleming et al., 2003; Gadamer, 2004). Based on the assumptions of the lifeworld there is always directedness, intentionality, between the subject and the phenomenon and knowledge concerns subjective understanding which can never be complete or an absolute truth. Ricoeur (1976, 2005) suggests one interpretation as the most probable, based on the experience and knowledge we have right now, which with time will probably be 'wrong' or need to be modified.

5.2.2 Phenomenological hermeneutical interpretation

Phenomenological hermeneutic interpretation is a method developed by Lindseth and Norberg (2004), further described by Fagerberg and Norberg (2009) and inspired by the philosophy of Paul Ricoeur. The method has its roots in phenomenology and the understanding of the lifeworld. With a lifeworld approach phenomenological hermeneutic interpretation focuses on lived experience, understanding and meanings, where meanings become visible in a dialectic movement between understanding and explanation of a text (Lindseth & Norberg, 2004). The method is a constant dialectic movement between parts of a text and the whole text, described as the hermeneutic arc (Ricoeur, Kemp & Kristensson, 1993). The method consists of three stages; naïve understanding,

structural analysis and a comprehensive understanding. It is not a linear process but a movement in two directions whereby explaining something in the text gives a new understanding which in turn needs to be explained, in a constant interaction. This process can be seen as a validation where parts of the text are understood based on the whole of the text and the whole of the text can be understood through its parts. According to Amdal (2001) Ricoeur's hermeneutic arc combines a movement from existential understanding to explanation and from explanation to existential understanding. Ricoeur (1976, 2005) suggests it is in the relationship between being familiar with and keeping a distance from the text that new meanings can become visible. Being familiar with the text is stressed in the naïve understanding and in the comprehensive understanding, while in the structural analysis distance from the text is maintained.

Phenomenological hermeneutical interpretation was used for studies **II** and **IV**. In study **II**, data from the third interview occasion when participants had had their diagnosis for three years was analyzed. In study **IV**, only text concerning trigger situations was analyzed with all 39 interviews being taken into consideration. In study **IV**, the interviews were read through in order to identify situations narrated verbally, such as “feels uncomfortable, “can’t manage this”, “don’t know how to cope” or “this bothers me”. In total 59 trigger situations were identified, which were then extracted from the rest of the text to be analyzed. The same situation could be narrated on different interview occasions by the same participant which were then brought together as one situation. The following analytic steps were similar for study **II** and **IV**, in line with Lindseth and Norberg's (2004) description. In the naïve understanding, the text was read to get a sense of the material in its entirety. A first naïve understanding of the text was formulated, aiming to grasp the meaning of the text as a whole on a descriptive level, as a ‘first guess’ of what the text was about. In the next step the structural analysis aimed to identify parts and patterns of meanings and to seek explanation of the text. The text was 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. In an ongoing process, subthemes, themes and the main theme were formulated. The back and forth process also involved the naïve understanding being modified in relation to the structural analysis as a form of validation. The structural analysis for study **II** resulted in two themes and five sub-themes and

for study **IV** in one main theme and four themes. Lastly a comprehensive understanding was formulated. The comprehensive understanding aimed to deepen the findings and provide a contribution to an ongoing discourse within the research area. The naïve understanding, the subthemes, themes and the main themes together with the authors' interpretation, including pre-understanding as well as relevant literature, were used to deepen the understanding of the studied phenomenon as a whole (Lindseth & Norberg, 2004).

5.2.3 Qualitative inductive content analysis

Qualitative inductive content analysis, a frequently used method in nursing research (Elo & Kyngäs, 2007), was used for studies **I** and **III**. Qualitative inductive content analysis is described as a process of identifying similarities and differences in the content of the text which are then abstracted into categories and themes (Graneheim & Lundman, 2004). According to Schreier (2012) the method is used to describe content on a manifest level as well as to interpret meanings of the text, referred to as the latent message (Graneheim & Lundman, 2004). In the present thesis the analysis has been carried out with assumptions in line with a lifeworld approach with its ontology and epistemology of a qualitative paradigm, involving interpretation and subjectivity. Elo et al. (2014) describe the researcher as having to judge which interpretations are most appropriate for a particular research problem. Graneheim and Lundman (2004) describe the theoretical assumptions in qualitative content analysis as based on communication theory (e.g. Watzlawick, Beavin Bavelas & Jackson, 1967) where interaction between researcher and participant as well as between researcher and the text are essential.

There are various ways of developing categories or themes from a text. For study **I** the analysis involved meaning units, condensed meaning units, abstracted meaning units, sub-themes and themes, in alignment with the description of Graneheim and Lundman (2004). All of the interviews were first read through as one text 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 step meaning units were condensed and abstracted, compared and interpreted into ten sub-themes and four themes.

In study **III** the interviews were analyzed separately at first (one interview at a time), then on an individual level (all three interviews per individual participant) and finally on a group level (39 interviews). This was done in order to be able to describe patterns of learning. After the initial reading of the interview, the text was divided into meaning units, which were condensed, abstracted and compared. The meaning units were sorted into subcategories, and then brought together into categories. As a next step a theme was formulated based on the thread of similarities found in the subcategories and categories for each interview (Graneheim & Lundman, 2004). Thereafter a summary was formulated based on the content of the subcategories, categories, and the theme for each interview. The question “How can the process of learning be described for this person?” was kept in mind. To be able to distinguish a pattern for each person focus was maintained on the changes and differences concerning the person’s thoughts, feelings, and management of their illness. A way of distinguishing a process is to focus on words summarizing the core of the text, compare those at different points in time and then identify shared aspects and any changes (Saldanã, 2003). As a final step, the individual patterns were compared with each other to see how they related to each other and shared commonalities were brought together to form main patterns (see Figure 1 for an illustration of the analysis procedure). The procedure in study **III** was inspired by different sources (cf. Auduly, 2013; Graneheim & Lundman, 2004; Saldanã, 2003). In order to distinguish the complexity of the process patterns were developed inductively. Saldanã (2003) describes the importance of focusing on complexity in order to understand the process, instead of a ‘from-to’ which tends to end up in a product description e.g. ‘what’ has been learnt.

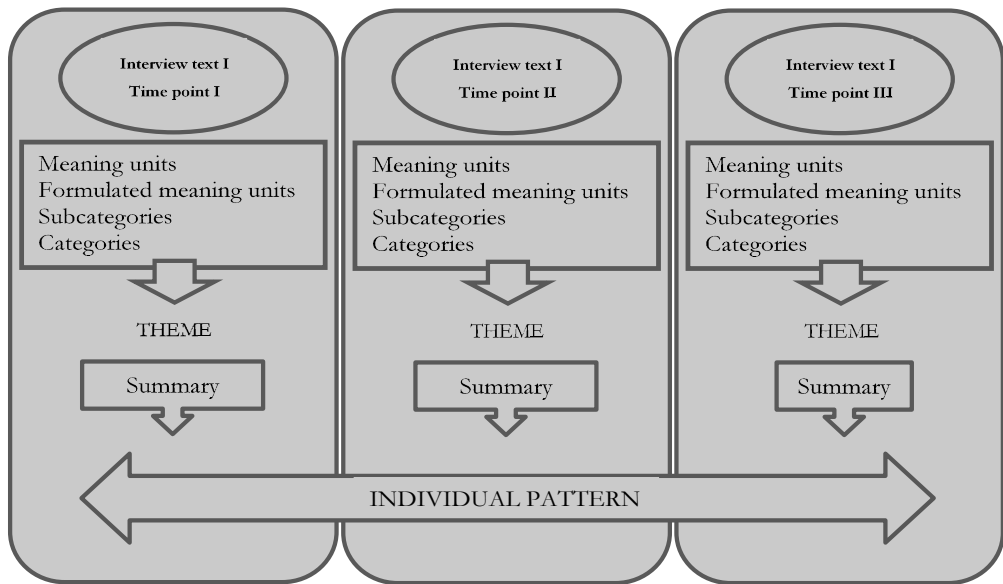


Figure 1: Schematic illustration of development of one individual pattern (Kneck, Fagerberg, Eriksson & Lundman, 2014. Living with diabetes: Development of learning patterns over a 3-year period. In *International Journal of Qualitative Studies on Health and Well-being*, 9(15), p.4. doi: 10.3402/qhw.v9.24375).

5.3 ETHICAL CONSIDERATIONS

Ethical considerations have been continuously taken into account throughout the research process. The studies have been conducted in line with the concerns raised by the Helsinki Declaration (World Medical Association Declaration of Helsinki [WMA], 2008) in relation to dignity and integrity for participants in a research project. The participants were guaranteed confidentiality and were informed of their right to withdraw from the study at any time as well as the fact that their participation was voluntary (All European Academies [ALLEA], 2013). They were also informed that interview data as well as any information on them was stored in a secure cabinet, in line with the right of self-determination, privacy and confidentiality of personal information of participants (WMA, 2008; ALLEA, 2013). Confidentiality was also ensured to protect the

participants from being recognized by quotations, something particularly important in the present study with a few participants from a limited geographical area. The studies were approved by the Regional Research Ethics Committee (Dnr 03-589 2010/640-32).

Ethical awareness was engaged in considering how participants involved in the study were met, treated and listened to at interview, as well as the risk, burden and advantages for participants enrolled in a study. Ethical considerations focused on protecting the participant by encouraging the person not to say more than the person actually wanted. As the interviews were aimed at participants sharing their lived experience the possibility of the participants becoming upset was considered. This was considered particularly in relation to the first interview occasion, as the participants had been newly diagnosed with diabetes, and a recent diagnosis of a lifelong illness often involves grief, fear and loss (Kralik et al., 2004; Mayan et al., 2006). The interview process also created an understanding of the importance of taking time and trusting the participants, believing that they had something valuable to contribute with. Ethical considerations for the interviews also concerned consciousness of body language of both the person being interviewed as well as the interviewer (cf. Kvale, 2007).

The interview situation brought awareness of the need for support services for participants in research projects while interview situations could trigger and influence the participant emotionally. At the same time one advantage of participating in the study was the opportunity to reflect and to be listened to, an opportunity to learn. Saldaña (2003) describes reflection on past changes as a way of stimulating future changes. The participants also expressed their gratefulness for being able to participate in the study.

6 FINDINGS

6.1 STUDY I

Four themes described learning to live with diabetes during the first months after diagnosis; *'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'*. ***Taken over by a new reality***; another reality was forced on participants when feeling unfamiliar with oneself and with the insecurity of how to manage new needs and a changed body. Reflection together with seeking information were ways to manage the new situation. There was a need to prioritize oneself and the diagnosis was a spur to reconsider the way one had lived and wanted to live and to make concrete changes.

The body plays a role in life; the body turned into a new player in life. A new awareness of the body meant insight into new demands. Bodily signals or symptoms made the body visible, and action had to be taken to satisfy the bodily needs. The glucose meter was a valuable tool for getting to know and understand the body with diabetes. To measure was to understand how the body worked and what influenced the glucose level; unexpected glucose levels or bodily symptoms also prompted reflection.

Different ways of learning; understanding and using information was complex and raised questions. It was difficult to know, for example, if information found on the Internet was trustworthy. Created situations through consciously trying something new, often in relation to food or activities, contributed to a new understanding. New experience was also gained from unplanned activities when previous routines could not be maintained. Feelings of being at the beginning of something together with being aware of the risk of complications created uncertainty. At the same time it was experienced as exciting to learn new things.

The health care service as a necessary partner; health care service was the rock to lean on, with reliable information and a safe place to turn to in case of uncertainty. However, when health care staff were not accessible or did not seem to be receptive to participants' acute specific needs the participants were disappointed, for example, when there was time only for discussions about medical doses and glucose levels, rather than for the concerns, questions and experiences from situations that they wanted to discuss.

6.2 STUDY II

The meaning of learning to live with diabetes three years after diagnosis were illuminated in two themes; *‘Learning to make decisions by using different sources of information’* and *‘Solving the life-puzzle – a delicate balance to create a desired life’*.

Learning to make decisions by using different sources of information; when receiving signs and symptoms from the body that could be interpreted and trusted the body was understood as a subject. Decision-making was a natural part of living and for feeling good in general, and taking care of oneself. Decision-making was also a constant struggle between contradictory needs and wishes, with bodily signs that were ignored when they could not be understood or given priority. Life was invaded by constant efforts related to illness demands which was hard seeing that it was for the rest of one’s life. Glucose measurement with the opportunity to take action based on glucose values increased the chances of doing what one wanted and of feeling free. At the same time glucose measurement became an obstacle, making it harder to rely on bodily signs. An objectified body with the uncertainty of one’s own needs and the interpretation of bodily signs, needed to be controlled by others with a dependency on health care for knowing the state of own health. Objective signs such as laboratory results, sampling, and glucose monitoring were important in understanding how the body worked. Insecurity arose when general information needed to be modified to one’s changing life situation and it was necessary to keep a grip of what one already knew.

Solving the life-puzzle – a delicate balance to create a desired life; balancing was to ask oneself what was most important and what was feasible in a specific situation and to let one’s own interests be the focus. Routines provided a structure beneficial to daily living, but it was also positive to let go of routines to try new things in life, and to put diabetes aside. Ignoring the demands of diabetes was to put aside one’s well-being. Independence from the health care service was preferred so that one could get on with one’s own life. Personal questions concerned how to handle life in general, but the focus in health care was medical treatment and blood glucose levels. Without a close relationship with the health care personnel it became harder to get care when required.

6.3 STUDY III

Five learning patterns were identified when living with diabetes for a three-year period;

Pattern I: *To find the balance, gradually letting oneself live*

Pattern II: *Active searching for knowledge to gain control*

Pattern III: *Despite obstacles have the strength to do what is important*

Pattern IV: *The hazards dominate when it becomes increasingly difficult to attain an acceptable blood glucose level*

Pattern V: *With knowledge and motivation adapt to minor changes in daily life*

Participants in Pattern I '***To find the balance, gradually letting oneself live***' and II '***Active searching for knowledge to gain control***' were active in their learning processes and experienced a trajectory from uncertainty to achieved control. To make limitations in daily life (in Pattern I) or expose oneself to problematic situations (in Pattern II) were different ways of managing insecurity. With time both ways was experienced being too demanding and redefinition of priorities and management become necessary. Participants in pattern III '***Despite obstacles, having the strength to do what is important***' had developed complications at the time of diagnosis. The body constituted a major obstacle to daily living and blood glucose control and lifestyle changes were secondary priorities in a chaotic existence until the third interview when life was more in balance. Participants in Pattern IV '***The hazards dominate when it becomes increasingly difficult to attain an acceptable blood glucose level***' found learning to live with diabetes increasingly difficult with time. Gradually being more dependent on routines for self-management but did not succeed in maintaining these. Knowing what to do was not enough with too many obstacles inhibiting change. Participants gradually became passive in managing illness demands with increased uncertainty of their own needs. Not feeling well neither bodily nor psychologically, together with dependency on the health care system, but having problems staying in contact with the system, hampered everyday life. For participants in Pattern V, '***With knowledge and motivation adapt to minor changes in daily life***' learning concerned adapting to different food and medication, something that required knowledge but within a limited area, and was considered as just an additional element in life. This differs from the participants in the other patterns as they experienced a more transformative process making a greater impact on them as a person, their health and their lives.

6.4 STUDY IV

The meanings of trigger situations in learning to live with diabetes were described in one main theme; *'Encumbered by vulnerability and temporality'* and four themes; *'Unsustainable situations'*, *'An unpredictable body and life'*, *'Dependability on oneself and others'* and *'The unforeseeable future demands.'* ***Encumbered by vulnerability and temporality;*** in trigger situations one's own vulnerability emerged with needs that could not be reconciled and with a fragile dependence on self and others. Temporality was apparent with uncertainty about the future, but also about that one had changed from previously.

Unsustainable situations; losing control in a complex situation involved one's whole existence being challenged with an earlier understanding of oneself, which was demanding but also an opportunity for learning. One's feeling of security was lost when routines could not be maintained and new demands not needed earlier had to be considered, making life difficult. Being required to act, such as being forced to choose between incompatible needs and circumstances over which one had no control was hard, with choosing to do nothing as an alternative.

An unpredictable body and life; when bodily reactions and blood glucose values were unpredictable or one did not feel well the body came into focus. To misjudge the body or wishing to be capable of acting differently was frustrating and triggered a need to avoid painful experiences in the future. Situations in social settings were familiar but also different as one did not have the same options to participate as before.

Dependent on oneself and others; collaboration with others was important for one's well-being but was also fragile. Others' insufficiency hampered living with diabetes which was frustrating. Dependent on managing the situation oneself was to feel alone and helpless, but also an opportunity for understanding more. In trigger situations social demands and expectations appeared that could not be fulfilled, with other needs also having to be considered.

The unforeseeable demands of the future; in trigger situations insecurity arose from not knowing what to expect. Questioning one's ability to understand and manage a changing life were reasons for worry and triggered reflection and planning. Past, present and future turned into a coherent whole with not only what was happening here and now being important, but also situations that might occur in the future.

6.5 SHORT SYNTHESIS OF FINDINGS

Time was a main concern in the present thesis with questions related to the importance of time when learning to live with diabetes. With the findings from studies **I-IV**, time was found to be interlaced with learning in different ways. Time was of importance for how the body was understood (**I, II**), the role of the health care (**I-III**) and what facilitated as well as hampered learning (**I-III**). However, a longer time living with diabetes did not per se mean an increased satisfaction in living well with illness or an increased confidence in understanding one's needs (**III**). Time was considered in relation to the present and the past (**I, IV**) with an insight into one's vulnerability when one was not sure how one would manage with the demands of the future (**IV**). These findings will be reflected and discussed in relation to other literature in the Discussion section.

7 DISCUSSION

7.1 DISCUSSION OF FINDINGS

The findings will be discussed under the headings '*contradictory situations important for a lifelong learning process*', '*a multifaceted process with different directions*' and '*a changing process with turning trajectories*'.

7.1.1 Contradictory situations important for a lifelong learning process

Contradictory situations were important for learning when living with diabetes, contributing to new understanding. Contradictory situations were described as being '*encumbered by vulnerability and temporality*', as trigger situations (IV), as well as '*taken over by a new reality*' (I) thus illuminating a life-altered situation when being newly diagnosed with diabetes. Contradictory situations shared the similarities of experiencing needs and demands and not knowing how to manage, interlaced with insecurity and frustration (I, IV). Ekebergh (2007) and Rager (2009) describe being emotionally affected, being engaged in a situation as a starting point for reflection and thereby for learning. Holmström, Larsson, Lindberg and Rosenqvist (2004) found reflection important for those living with illness as a means for new understanding to emerge. Riegel et al. (2012) describe reflection important for being able to perform diabetes related self-care and crucial for achieving mastery of self-care management. Learning needs were experienced in everyday life as common situations that were familiar before having diabetes but that with diabetes became unfamiliar, described in '*an unpredictable body and life*' (IV). These contradictory situations then illuminated that an existence that had been taken for granted was changed. Ekebergh (2009) describes reflection as raising awareness of phenomena that had otherwise just been taken for granted, as being able to see and understand in different ways than before. The insecurity and frustration experienced in a contradictory situation can further be understood as a loss of a smooth interconnection between the embodied subject and the situation (cf. Bullington, 2009). An illness experience is described by Gadamer (1996) as feeling homeless, hence learning can be understood as an attempt to feel at home again, to regain familiar and secure surroundings. Contradictory situations also

triggered reflection when earlier ways of life were questioned (I, IV). Insight into what is important in life is raised by Berglund (2014) as a learning turning point. Ingadottir and Halldorsdottir (2008) found reflection to be important in order to understand the consequences of changes needed for adhering to diabetes treatment and whether the changes meant to experience adding life to years or years to life when living with diabetes.

With findings from the present thesis learning was considered as informal and unplanned. It was situations that did not turn out in line with expectations that became potential learning situations, described in '*unsustainable situations*' (IV). Everyday living was therefore the platform for learning when living with diabetes. Kungu and Machtmes (2009) describe lifelong learning occurs in a myriad of settings. Learning to live with diabetes was also to be forced to manage situations in everyday life over which one had no control, such as being required to act in a complex situation when experiencing difficult conditions or facing social demands that one could not fulfil, and involving incompatible needs and wishes (IV). Riegel et al. (2012) state that living with a lifelong illness means decision-making in complex life settings which involves uncertainty, lack of information and time stress. Walker (1999, p.17) addresses that persons with diabetes have not chosen "this course of study", illuminating learning as involuntary.

In contradictory situations feelings of being changed emerged, described as '*encumbered by vulnerability and temporality*' (IV). According to Saldaña (2003) change is a comparison between at least two reference points e.g. a 'then' and a 'now'. To experience change is thus related to time and according to Merleau-Ponty, (1945/2002) time exists as a form of existence. A changed existence is thereby linked to a changed experience of time. In contradictory situations past experiences became important for new understanding to emerge, as well as for a different awareness of the future, described as '*the unforeseeable demands of the future*' (IV). Berglund (2014) describes patient education and health care information as concerning the present and the future, but a missing element is the focus of earlier experience, which is important for how information is understood. In the present thesis being aware of the unpredictability of what lay ahead was to try to understand what the present will mean for the future. Learning to live with diabetes was therefore both situated in

and influenced by time and in turn influenced time, as a lifelong learning process.

With new understanding and experiences, a contradictory situation became a qualitatively important period of learning for persons living with diabetes, in line with Saldaña's (2003) description of time. It seems reasonable to assume that additional insight and understanding can be gained from these situations if they are identified and recognized in health care encounters. Encouraging the person with diabetes to maintain a dialogue based on the experience from contradictory situations could therefore be a means of promoting learning. Dialogue is described by Mezierow (1998) as important for reflection and for promoting a shift in perspective, thus facilitating learning. By maintaining a dialogue based on experience from these situations health care can facilitate learning to live with diabetes, whereas not applying these experiences can leave the person with a feeling of being alone and helpless, described as '*dependent on oneself and others*' (IV). Dahlberg et al. (2009) describe lifeworld-guided caring as offering alternative ways for ill persons in their life journey to see themselves with all vulnerabilities and opportunities presented. A caring approach that has similarities with being a lifeworld researcher with understanding made from dialogue, being bodily present and with time, space, social and personal meanings being considered (Friberg & Öhlén, 2010). Holmström, Halford and Rosenqvist (2003) use the expression to seek knowledge relevant for the particular person. However, Jutterström, Graneheim, Isaksson and Hörnsten (2012a) found DNS in diabetes care to be mostly task-oriented. This was further explored as a role conflict with an experience of insecurity for nurses who were supposed to focus on the needs and experience of the person with diabetes instead of the delivery of information (Hörnsten, 2004; Thors Adolfsson, 2008). This emphasises the importance of a habitual role for a feeling of security, but also illuminates very different perspective on knowledge. For a person-centred approach based on dialogue a nurse will require skills and knowledge other than those demanded for a more task-oriented or disease-focused approach, which can constitute a shift in perspective (cf. Mezirow, 1991). Based on findings from both this present thesis and other studies (cf. Berglund, 2014; Berglund & Källerwald, 2012) the temporality and spatiality of the learning process needs to be considered in the health care encounters. How time and space are understood,

e.g. as experienced in contradictory situations, is thought to influence the direction of a person's interest and their opportunity to learn.

7.1.2 A multifaceted process with different directions

The learning process in this thesis was fluctuating to changing needs, transformative and developing as well as a more linear process of adaption to more or less constant needs (III). This illuminated a multifaceted process described also by others (cf. Hernandez, 1995; Kralik, 2002; Paterson, 2001; Price, 1993; Whittemore & Dixon, 2008). However, learning processes, self-management processes as well as illness integration processes are often described as processes in the direction of life becoming 'easier' with an existence more in balance and under control (Hernandez, 1996; Hörnsten et al., 2011; Paterson & Thorn, 2000; Person et al., 2010). For example, Moser, van der Bruggen, Spreeuwenberg and Widdershoven (2008a) describe the phases 'comprehending', 'struggling', 'evaluating' and 'mastering' as constituting a process of achieving autonomy for persons living with diabetes. To assume that learning to live with diabetes gradually becomes easier is to understand time as a smooth, linear process (Saldaña, 2003). However, in this thesis the direction of learning was diverse with the experience of living becoming both easier with time as well as increasingly difficult when trying to live well with diabetes (III).

From a lifeworld perspective living is to be engaged in a complex process of movement and development (Dahlberg et al., 2008). However, in that movement every person has a particular perspective on their existence, involving a directedness or, intentionality (Merleau-Ponty, 1945/2002). The directedness of the movement or what is to be learned in a learning process can be described as the focus or the interest of that particular person in that particular situation. Responding to a situation without changing is addressed by Jarvis et al. (2003) as common even when learning needs emerge. Knowles et al. (2005) emphasize that there needs to be a 'readiness' stage in order to learn, as well as that adults will be willing to devote energy towards learning if they perceive it will help them to deal with problems or tasks in their everyday life. This illuminates the importance of trusting one's own ability to learn and the positive impact that learning in a certain direction would have. This differs from the insecurity and inability to understand needs, which was found to be associated with a

resignation in relation to be active in learning, described in the learning pattern *'the hazards dominate when it becomes increasingly difficult to attain an acceptable blood glucose level'* (III). When persons living with illness do not seem to learn it is often referred to as a resistance to learning. Berglund (2014) described one reason for a resistance to learning being the fact that any changes were not self-chosen but were instead dictated by the illness. Resistance to learning is further described as focusing on being able to live and being the same person as before despite a diagnosis of diabetes (Johansson, Ekebergh & Dahlberg, 2009). Other interests may take precedence for persons with a lifelong illness, such as caring for other persons, or activities other than caring for oneself (cf. Berglund, 2014). Jansink et al. (2012) found that persons with elevated glucose levels would not pay attention to health care information if they believed it was not relevant to them. This illuminates the complexity of the learning process when living with diabetes and the importance of the picture and future scenarios of the illness that the person living with diabetes has in his/her mind. Readiness, when the person is willing and interested in learning, needs to be further assessed (cf. Knowles et al., 2005). Identifying the person's focus of interest is considered to be a beneficial first step if learning is to be considered an option.

In this present thesis the same trigger could both hamper as well as facilitate learning, illuminating a multifaceted process. Feeling insecure (III) and vulnerable (IV), such as experiencing that one's existence is threatened, could trigger an engagement in learning, described as *'to find the balance, gradually letting oneself live'* and *'active searching for knowledge to gain control'* (III) and as being *'encumbered by vulnerability and temporality'* (IV). Berglund (2014) emphasizes the need for feeling one's existence is threatened in order to be engaged in learning. At the same time a learning turning point in Berglund's study was to change a dark picture of the future to a more nuanced one. However, in this present thesis increased insecurity could also mean the opposite, creating a more passive approach to learning, described as *'the hazards dominate when it becomes increasingly difficult to attain an acceptable blood glucose level'* (III). Obstacles did not per se hamper learning, as described in *'despite obstacles, having the strength to do what is important'* (III). However, obstacles could inhibit the learning process by making it difficult to make the necessary changes to live as one wanted and to experience well-being (III).

Obstacles can further create a situation where there is a lack of valuable options to choose from and thus a limited freedom to choose. Jacob (1994) addresses limited freedom to choose as limiting one's ability to take responsibility for one's situation. If persons living with diabetes are to achieve mastery (cf. Meleis et al., 2000) making independent choice and feel personal responsibility for their own health they need to have valuable options to choose from. Learning to live with diabetes is therefore a process influenced by both individual as well as societal conditions. Personal conditions were in the present thesis described as *'active searching for knowledge to gain control'* and *'despite obstacles, having the strength to do what is important'* (III), and external conditions, such as others' insufficiency hampering living with diabetes, as *'dependent on oneself and others'* (IV). Hence, interventions for persons with diabetes need to be focused on conditions influencing the learning process on both the individual and social level. Based on the findings from the present thesis it is important for understanding and supporting learning to illuminate how the complexity in daily life can facilitate as well as hamper learning. However, most health care interventions concern formal learning with predefined goals, activities and content (Tshianaga et al., 2012). Likewise diabetes research mainly focuses on the intervention provided by health care personnel in health care settings, such as different approaches to patient education (cf. Carbone, Lennon, Torres & Rosal, 2005-2006; Coulter & Ellins, 2006; Ellis et al., 2004; Glasgow, Toobert, Mitchall, Donnelly & Calder, 1989; Horwitz, 1993; Kandula et al., 2009).

The complexity of the process was also portrayed as the interlacement of learning and health when living with diabetes. A need for learning was experienced when feeling physical and psychological malaise. The aim of learning was to gain control and for existence to be in balance, described as *'solving the life-puzzle – a delicate balance to create a desired life'* (II) and *'active searching for knowledge to gain control'* (III). Control and balance are further described as important elements of mastery and an outcome of a healthy transition (Meleis et al., 2000). Rasmussen et al. (2007) describe being in the grip of blood glucose levels, referring to different levels of control in relation to emotion, life and health. The ambiguous meaning of routines further illuminated the interlacement between learning and health. Routines provided security and manageability in one's existence and a sense of control. However, letting go of routines was to expose oneself to new experiences, with the risk of becoming

vulnerable and losing control, but at the same time offering an opportunity for learning (II, IV), described as ‘*unsustainable situations*’ (IV). Learning to live with diabetes also meant being worried about the future described as ‘*unforeseeable demands of the future*’ (IV). Dahlberg et al. (2008) described impaired health often arising when one’s desired future became threatened. Learning to live with diabetes concerned learning to feel well in general and being able to do what one wanted in life (II, III) in line with the definition of well-being and fulfilment of personal goals as an aspect of health. Moser et al. (2008a) describe a resumption of autonomy as a process of having the competency to shape one’s life.

Questions related to living with diabetes in a broader aspect than only those related to treatment and metabolic control were of particular interest, when one could get on with one’s life projects, described as ‘*solving the life-puzzle – a delicate balance to create a desired life*’ (II). Being able to focus on one’s own life projects is further described as experiencing health (Dahlberg et al., 2009) and having a perspective on ‘wellness in the foreground’ (Paterson, 2001). However, in health care the focus was on blood glucose and medical treatment which, despite being appreciated, was at the same time experienced as not being enough, described in ‘*the health care service as a necessary partner*’ (I). Several studies have found similar findings (cf. Hörnsten & Graneheim, 2009; Thors Adlofsson, Starrin, Smide & Wikblad, 2008). Hörnsten and Graneheim (2009) found that persons living with diabetes experienced that nurses focused on medical parameters instead of listening to the person’s own experience and needs. Thors Adlofsson (2008) found that most counselling time was spent on issues other than the patient’s own problems. However, Peyrot and Rubin (2007) found that identifying strategies to overcome the person’s own obstacles was important for health care personnel so that they could help persons with lifelong illnesses to attain their health related goals.

7.1.3 A changing process with turning trajectories

Over time a change in understanding was addressed in relation to the body, one’s own priorities and self-management (I-III). A change in understanding could be related to a shift in perspective, described by Mezirow (1991) as learning. However, in this thesis these shifts in perspective did not align with the

definition of a turning point as a sudden shift in meaning and engagement (King et al., 2003). In this thesis it was instead insight gained from complex trigger situations (IV) or a redefinition resulting from a combination of insights from different situations (III) that resulted in a shift in perspective. This is different from Jutterström et al. (2012b) who describe a sudden insight indicating a need to act differently, which is important for the person's illness integration process. This is in line with Meleis et al. (2000) who defined a 'critical event' which is understood to have a distinct position in time and place. In the present thesis a shift in perspective was found to have a broader definition than that of a critical event or a turning point, with an extension over time, involving the past, present and the future, illuminating a turning trajectory. Turning trajectories were portrayed in the patterns '*to find the balance, gradually letting oneself live*' and '*active searching for knowledge to gain control*' (III).

With time and experience, with interaction between the body and the world the understanding of the body changed. The body, as well as blood glucose, was interpreted both objectively and subjectively (II). Initially the body was described as a 'new player in life' (I), involving an distancing and objectification, described as one having to understand 'the new body' as something separate from oneself. Distancing can provide an altering perception, important for learning (cf. Berglund, 2014). Initially the person needed to be able to see the body both before and after getting diabetes, a changed body (I). However, with continued experience and the body continually changing the body became seen as unpredictable (IV). Ingadottir and Halldorsdottir (2008, p. 617) described being "embodied in an ever unpredictable and changing body". To lose the image of the body and self one was used to, triggered a need to learn in order to go on with one's life, described as '*the body plays a role in life*' (I) and '*unsustainable situations*' (IV). To mistrust the body as well as encountering signs and symptoms that were hard to interpret was associated with insecurity and dependency on others (I-II, IV). This insecurity can be understood in terms of lost bodily competence in relation to habits that were once effortless and automatic performed. Bodily competence is dependent on being able to relate to what has already been since habits are repetitions of the past (Talero, 2006). To know how to manage a particular situation is described by Galvin and Todres (2011) as embodying rational understanding. However, learning to live with diabetes can be described as learning to live with a changed body with a need to

create new habits that enable an automatic performance in life, illuminating learning as another way of living. Merleau-Ponty (1945/2002) describes the body as the vehicle for our being in the world, our connection to the world, and Bullington (2009) illuminates the changes to the structures of one's life as also experiencing the world to be changed.

What facilitated for learning changed with time and had to be understood and revalued with new experience. Examples were the understanding of the glucose meter and information that changed over time according to how the learning process developed (**I, II**). The need for health care support also changes with time for the person with diabetes (**I-III**). After three years living with diabetes, both becoming gradually more independent from health care as well as experiencing a need for health care support were found (**II-III**). Health care intervention early in the learning process is often stated as beneficial as the understanding of one's illness is important for further self-management (Tahmasebi, Noroozi & Tavafian, 2013). Supplying information soon after diagnosis is therefore common (cf. Krichbaum, Aarestad, & Buethe, 2003; Toljamo & Hentinen, 2001) with the purpose of decreasing the risk in the long term for future complications (Funnell et al., 2011). However, in this present thesis problems with information concerned more how to interpret information than dealing with the lack of it (**I**), making the point that just knowing what to do was not enough for a sense of well-being (**III**). Hutchinson and Hall (2007) point out that information technology offers access to information whenever and wherever it suits those with a life-long illness. At the same time one should be aware of the varying quality of information presented on the internet. The ability to modify general information to meet one's own physical and psychological needs has been found important for the learning process when living with diabetes (Hernandez, 1995; Price, 1993). However, in this thesis interpreting and understanding one's own needs was considered difficult, seen as a constant struggle (**II**) and interlaced with becoming passive in managing the demands of one's illness (**III**). Health care can play an important role as a 'translator' for the person in understanding general information to cater for the person's individual conditions and needs. However, in this thesis the issue was also addressed of the difficulties of staying in contact with health care with longer illness duration, especially hard when one needed support (**II, III**). On the other hand, health care is organized based on the type of diabetes and medical treatment and not directly

on patients' needs (NDR, 2013; National Board of Health and Welfare, 2012). The findings of the present thesis show that flexibility in health care is needed for meeting the needs of persons living with diabetes. With a longitudinal design and with the opportunity to illuminate learning to live with diabetes at different times the present thesis shows that the learning needs of persons living with diabetes change as different situations mean new needs and demands over time.

7.2 METHODOLOGICAL CONSIDERATIONS

All research, independent of approach and method needs to have rigour, often referred to as the reliability and validity of a study. A parallel concept to rigour in qualitative studies is trustworthiness (Morse, Barrett, Mayan, Olsson & Spiers, 2002). Credibility, transferability, conformability and authenticity as aspects of trustworthiness have been addressed in this thesis in line with epistemological assumptions (cf. Elo et al., 2014).

7.2.1 Design

The present thesis, involving four studies using phenomenological hermeneutical interpretation as well as qualitative inductive content analysis, has a lifeworld approach. The chosen research approach was considered appropriate for addressing the overall aim of the thesis as the lived experience was of interest and in line with chosen lifeworld definitions of learning and health. It was considered that a philosophical framework with an integrated coherent approach between the research questions, data collection, analysis and reference literature for the entire thesis would enhance the credibility of the thesis (cf. Koch, 1996; Morse et al., 2002). Ontological and epistemological assumptions of lifeworld research have been stressed in order to enhance credibility (cf. Walsh & Downe, 2006) and can be considered a strength. Even if Dahlberg et al. (2008) question qualitative content analysis being used in lifeworld research it is considered that the focus on the lived experience and understanding in relation to the phenomena is the essence of lifeworld research. It can be considered a limitation that this thesis has only focused on the subjective perspective of health, illness and learning. By adding different perspectives, such as biomedical and objective measurement to the overall aim of the study, a more comprehensive understanding of the learning process of living with diabetes could have been reached. Even if some additional clinical characteristics of the participants were

provided by the participants themselves (see Table 2), the level of objectivity that bio-medical measurement requires cannot be guaranteed. Interviews were the only source of data, which can be considered as a limitation, as van Manen (1990) and Koch (1994) address the need to use multiple sources for a more extensive understanding of a phenomena. However, Bengtsson (2005) advocates using the same research approach for different studies as a way of achieving cumulative knowledge of the phenomena and this can therefore be an advantage. It was also considered that the interviews provided an opportunity to deepen the understanding of learning in a lived and subjective perspective, a seldom explored area of research.

One advantage of this present thesis was its longitudinal design enabling an emphasis on the importance of time, which as well as being relevant for the overall aim of the study is also a missing element in existing research on diabetes. However, there is no definitive answer to the question of how long a longitudinal study has to be in order to be considered longitudinal (Saldaña, 2003). Consideration can be given as to whether, and in which case how, data would have been richer with more frequent follow up interviews or had been collected over a longer period. The choice of data collection over a three-year period is in some way based on an assumption of time as chronological and linear and that therefore implicitly development and learning follow a chronological line. However, in the present thesis learning was found not to be linear or based on chronological time (III). On the other hand the longitudinal design was found to generate more unstructured data, not framed by fixed or short answers, as participants, with time, were more comfortable in the interview setting narrating their own experiences. Unstructured data enhances the possibility for an inductive approach and this was considered as an advantage (cf. Neuendorf, 2002). It was considered that a longitudinal design would decrease the risk for recall bias, as situations and experience from the recent past could be captured instead of just experience from many years ago. This is a common procedure in most studies in the research field that employ a retrospective design (cf. Paterson & Thorne, 2000).

7.2.2 Data collection and analysis

It is considered that the method, and description of the method, of selection of participants will enhance credibility and transferability of the study results. A purposive sample was considered appropriate, with the aim of increasing the possibility of capturing a variety of experiences (cf. Patton, 2002). However, it is impossible to say to what extent the purposive sample contributed to the diversity in the learning process reached in this thesis. It is considered a major advantage that all participants chose to remain throughout the data collection process, something that could not be taken for granted as Saldaña (2003) says with regard to participants dropping out of a study, “be prepared but expect the unexpected” (p.16). Study III was possible to conduct as there was no drop outs, raising a risk of illuminating phenomena based only on certain persons individual participation. The number of participants in qualitative studies is not as important as the richness of data which guides how many participants to include (Sandelowski, 1995, 1999). In the present thesis it would have been preferable to include more participants if some had decided to drop out. It is usual to let the participant chose the setting for the interview, but one must ask if the hospital setting contributed to short answers, as well as to the focus on metabolic control. Participants were found to be more confident when telling everyday experiences when interviews were conducted outside the hospital (second and third interview occasions). Koch (1994) states that it is easier to talk about own experiences when feeling ‘safe’ at home.

Interviews as the source for data were considered appropriate as they provide an opportunity to share another person’s lifeworld (van Manen, 1990), which is important for capturing the lived experience. A way of achieving credibility for the thesis was to conduct a pre-interview to enable the development of suitable interview questions (cf. Elo et al., 2014). The pre-interview aimed to determine whether the interview questions were suitable for capturing rich data in relation to the aim of the study (Neuendorf, 2002). The pre-interview was conducted with a person who had had diabetes for some years. However, in retrospect it would probably have been better with a person recently diagnosed with diabetes in line with the participants in the study, so that questions could, if necessary, have been modified accordingly. It was a conscious decision not to use the words ‘learn’ or ‘learning’ in the interview questions in line with Kolb’s (1984) understanding of

learning as something taking place without one being aware of it. Lindseth and Norberg (2004) found that in everyday life persons are seldom conscious of the meaning of phenomena. It was also considered to be a risk that using the word 'learning' would result in a focus on 'what' had been learnt thus losing the opportunity to focus on the learning process. Ekebergh (2001) found that most didactic studies concern the 'what' and not the 'how' question, thus failing to address the core of a complex learning process. It would, however, have been interesting in the pre-interview to try out interview questions involving the word 'learning' in order to see how the participant would have responded.

Even if all studies were based on interviews with the same participants it has been a distinction in how the data have been used for different aims in the studies. The choice of analysis method for the available data was guided primarily by the need for credibility (Elo et al., 2014; Polit & Beck, 2012). For study **I**, based on interviews from the first interview, part of the data was considered to be fragmentary and a qualitative content analysis was therefore considered appropriate, allowing different levels of abstraction based on the available text (Graneheim & Lundman, 2004). At the third interview (**II**) participants freely narrated about their experiences of living with diabetes, providing richness in data enabling an interpretative analysis with a high level of abstraction. In study **III**, where patterns in learning were described, content analysis was considered the best choice for managing such an amount of longitudinal data. However, study **III** proved a methodological challenge and needed "creative artistry of the analysis to make sense of it all" (Saldaña, 2003, p. 62), involving inspiration from different sources (Saldaña, 2003). Analyzing individual data initially in time phases by creating an individual, chronological indexing system was fruitful. For study **IV** only the situations that were narrated with meanings related to trigger situations were considered for analysis. In the present thesis all data was collected before analysis of data was conducted. However, continuous analysis during data collection would probably have been beneficial for reaching a better overall understanding of the data provided (cf. Elo et al., 2014). Data was collected between 2004 and 2007 and continuous analysis of data would probably have accelerated the process of arriving at the findings. However, still lack of longitudinal studies and studies capturing learning from a lived and subjective perspective represents a sparsely researched field.

In this present thesis conformability has been considered in line with Sandelowski (1986) and Koch (1994), who describe conformability as another researcher arriving at a comparable conclusion given the same data, perspective and situation, also making it be possible to follow the way in which the researcher came to his/her findings. To enhance conformability in line with Sandelowski (1986) and Koch (1994) a number of different procedures were used, such as transcription, analysis, findings being shared with different researchers, seminars considered as ‘peer debriefing’ and articles being submitted for review (cf. Polit & Beck, 2012). Sharing findings with others was also a way of ensuring awareness of one’s own pre-understanding and increased the likelihood of being open to the phenomena of interest, also referred to as the credibility of a study (Dahlberg et al., 2008; Drew, 2001; Flemings et al., 2003). A description of the different steps in the analysis process has been provided to enhance credibility as well as the transparency of the study (Drew, 2001; Guba & Lincoln, 1989; Polit & Beck, 2012). The abstraction process, however, can be difficult to describe since interpretation is subjective and there is an interaction between the interviewer and the interviewee, as well as between the reader and the text. As Mounier described (1950/1952, p.10) “one cannot speak of any object, still less of a world, except in relation to a consciousness that perceives it”, which is in line with the epistemological assumptions for this thesis.

7.2.3 Presentation of findings

For the presentation of findings for this thesis it was important to use material that was up to date when choosing relevant literature, as well as to consider the appropriate concepts to be discussed. The intention has been to enhance the authenticity of the thesis so as to highlight the research area and findings as both crucial and relevant for today’s clinical practice and the research field (cf. Elo et al., 2014). Another way of enhancing authenticity has been to describe the lived experiences of the phenomena using everyday language (cf. Lindseth & Norberg, 2004). Polit and Beck (2012, p.585) described this as the “tone of participants’ lives as they are lived”.

In this present thesis there is an assumption that qualitative data is contextual. However, participants and context descriptions, have been provided in order to enhance the transferability of the findings to other settings, in line with Schreier

(2012) and Elo et al. (2014). Guba and Lincoln (1989) address transferability as 'fittingness' so that findings can 'fit' into a context outside the study situation. Since learning is a universal phenomenon and diabetes is a worldwide disease, commonality with persons learning to live with diabetes in other parts of the world can be considered. Learning to live with diabetes also has similarities with learning to live with other lifelong illnesses and findings from this thesis could therefore be considered to 'fit' into contexts other than purely that of diabetes care.

8 CONCLUSIONS AND IMPLICATIONS

Time living with diabetes influences the learning process in different ways. A changed understanding of one's body and the role of health care as well as what facilitates and hampers learning occurred over time. To developed mastery of a changed life situation the longer one lived with diabetes, but also experienced increased difficulty in understanding one's needs and maintaining well-being was found. Over time the process of learning to live with diabetes was constantly changing and multifaceted, and involved different learning patterns for different persons. Contradictory situations were interlaced with a loss of sense of well-being, but presented learning needs and provided an opportunity for learning as a qualitatively important period for understanding more. Learning to live with diabetes was a lifelong process where the past, the present and the future were important for how one understood one's changed life circumstances. Learning to live with diabetes was informal, often unplanned and involuntary, and experienced in everyday life and in different situations. Learning involved shifting perspective and a changed understanding occurring over time as a turning trajectory with different directions. For the person living with diabetes one purpose of learning was the longing to create a desired life and a sense of general well-being.

-Health care personnel can play a significant role in the learning process for persons living with diabetes by stimulating reflection, thus allowing new insights to emerge and by clarifying of learning needs.

-A dialogue based on the individual experience of the person with diabetes of contradictory situations and an understanding of what facilities or hampers learning in everyday life settings presents a route towards person-centred care.

-The past, the present and the future need to be considered in a dialogue, as an understanding of time influences a person's 'readiness' to learn and their willingness to change and make changes.

- Health care support needs were different for different persons and changed over time. Health care thereby needs to be organized in such a way that it can respond to the varying needs occurring over time.

9 FURTHER RESEARCH

Life-long learning is important for health and associated with individual fulfilment of personal goals as well as the development of human capital (cf. Kungu & Machtmes, 2009). Hence, the learning process when living with diabetes needs to be further explored, because it is of interest for persons living with the illness as well as for health care and for society as a whole.

Areas for future research are;

- How health care intervention can be designed and evaluated from a lifelong learning perspective.
- How a health care encounter between a person with diabetes and a nurse specialized in diabetes care could be person-centered instead of task-oriented and still fulfil the requirement to systematically report data.
- How health care interventions aiming to support learning and self-management for persons with diabetes could be conducted in daily life settings instead of just the health care environment.
- If and how enhancing pedagogic knowledge and didactic skills for nurses would influence the learning process for persons living with diabetes.

10 SWEDISH SUMMARY

En livslång sjukdom som diabetes innebär ofta både kroppsliga och sociala förändringar samt en förändrad självbild. Den dagliga livsföringen påverkas också med nya rutiner och förändringar i tidigare sätt att leva. De nya krav och behov som sjukdomen medför måste den enskilda personen lära sig att hantera. Hur personen lär sig leva med sin sjukdom blir viktigt för upplevelsen av att känna kontroll och hälsa. Trots att diabetes är en livslång sjukdom förenad med många förändringar och behov av anpassning så är tidens betydelse för lärandeprocessen i livet med diabetes sparsamt studerat. Att bättre förstå tidens betydelse för lärandet i livet med diabetes är av yttersta vikt för att kunna utforma sjukvårdsinsatser utifrån personer med diabetes individuella behov, en förutsättning för en personcentrerad vård.

Denna avhandling tar sin utgångspunkt i livsvärldsteorin och teori om livslångt lärande. Det övergripande syftet med avhandlingen var att få fördjupad förståelse för lärandet i livet med diabetes de tre första åren efter diagnos. Avhandlingen har en longitudinell, kvalitativ, beskrivande och tolkande ansats. Data till de fyra delstudierna samlades in genom intervjuer med tretton personer, diagnostiserade med antingen typ I eller typ II diabetes. Personerna intervjuades vid tre tillfällen; en till två månader efter diagnos, ett år efter diagnos och tre år efter diagnos. Intervjuerna inleddes med frågan 'hur upplever du det att leva med diabetes' för att senare i intervjun beröra frågan 'kan du berätta om någon situation där det blivit tydligt att du har diabetes'. Intervjuerna skrevs ut ordagrant och analyserades för delstudie **I** och **III** med kvalitativ innehållsanalys och delstudie **II** och **IV** med fenomenologisk hermeneutisk metod.

I studie **I** beskrevs lärandet för personer som nyligen blivit diagnostiserade med diabetes. Resultatet beskrevs utifrån fyra teman; '*överrumplad av en ny verklighet*', '*kroppen tar plats i livet*', '*olika sätt att lära*' och '*sjukvården en nödvändig partner*'. Studie **II** beskrev innebörden av lärandet tre år efter diagnos. Två teman framkom; '*att lära sig ta beslut genom att använda olika källor för information*' och '*att lösa livspusslet – en delikat balansakt för att möjliggöra det önskade livet*'. I studie **III** beskrevs olika mönster i lärandet över

en treårsperiod. Mönstren benämndes; *'finna balansen – att successivt tillåta sig att leva'*, *'aktivt sökande efter kunskap för att känna kontroll'*, *'trots hinder ha styrkan att göra det som är viktigt'*, *'riskerna dominerar när det blir allt svårare att uppnå acceptabla blodsockernivåer'* och *'med kunskap och motivation anpassa sig till smärre förändringar i vardagen'*. I studie IV beskrevs innebörden av situationer som triggar lärandet i livet med diabetes. Ett övergripande tema; *'översköljdas av sårbarhet och temporalitet'* samt fyra teman; *'ohållbar situation'*, *'kroppen och livet som oförutbestämt'*, *'beroende av en själv och andra'* samt *'framtida oförutsebara krav'* beskrevs.

En syntes av resultaten i studierna visade att förståelsen av kroppen, sjukvårdens betydelse samt vad som underlättar och försvårar lärandet förändras över tid. Längre sjukdomsduration innebar att livet kändes mer i balans och med ökad egenförmåga att hantera den förändrade livssituationen men kunde också innebära ökad svårighet att förstå egna behov. Lärandeprocessen vid diabetes beskrevs som föränderlig, mångfacetterad och med olika lärandemönster för olika personer. Komplexa situationer med en känsla av förlorad kontroll och sårbarhet innebar möjlighet för lärande. Att lära sig att leva med diabetes beskrevs som en livslång process där det förflutna, nuet och framtiden var viktiga för att förstå den förändrade tillvaron. Lärandet beskrevs vidare som informellt, ofta oplanerat och ofrivillig samt utgjordes av erfarenheter i vardagen. Vårdpersonal kan ha en betydelsefull roll för lärande processen hos personer som lever med diabetes. Genom att stimulera reflektion kan nya insikter och identifiering av lärandebehov ske. En dialog baserad på personen som lever med diabetes egna erfarenheter i uppkomna komplexa situationer och förståelse av vad som underlättar och försvårar lärandet i vardagen är ett sätt att uppnå en personcentrerad vård. Att fokusera både på det förflutna, på nuet och på framtiden är, baserat på avhandlingens resultat, viktigt då förståelsen för hela detta tidsförlopp påverkar personens vilja att förändras och göra förändringar. Eftersom behovet av stöd från sjukvården skilde sig mellan personer och förändrades över tid behöver sjukvården vara organiserad på ett sätt att den kan anpassa sig efter personers behov. Ett sjukvårdssystem som möjliggör följsamhet

till personens individuella förutsättningar och problem är en förutsättning för en personcentrerad vård.

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