Illness integration, self-management and patient-centred support in type 2 diabetes

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“Not everything that can be counted counts, and not everything that counts can be counted.”

To Magnus, Caroline, Wilhelm, with love. You are everything to me
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Abstract

Background: Type 2 diabetes is a serious disease that is increasing globally. The focus of diabetes care has been to prevent diabetes related complications and thereby reduce mortality. An older population, the disease progression and decreased ability to perform self-management activities increases the risk for complications. Group education and patient-centred care are recommended to improve self-management through increased patient empowerment. Despite these recommendations, professionals have been reluctant to adopt these methods referring to lack of knowledge, time and tools to deliver patient-centred care in diabetes. Focusing on the patient’s illness integration process has in the literature been suggested to improve self-management and metabolic balance.

Aim: The overall aim of the thesis was to describe the experiences of illness integration, self-management and support in type 2 diabetes and to evaluate the metabolic effects of a nurse-led patient-centred model for self-management support.

Methods: The study setting was primary health care in Västerbotten County, Sweden. In total, 21 diabetes nurses (Study I) and 257 patients (Studies II-IV) participated in the four studies (Study II, n=44; Study III, n=18; Study IV, n=195). Data consisted of focus group interviews (Study I), individual semi-structured interviews (Studies II-III) and laboratory measurements (Study IV). Methods for analyses were qualitative content analysis (Studies I-III) and statistics (Study IV).

Results: Study I revealed that diabetes nurses found the ideal diabetes care complex to achieve. Conflicting paradigms, power relations and departmentalisation of work were described. Study II describes a process whereby illness integration and self-management in type 2 diabetes develop simultaneously. When a turning-point occurs, people view self-management as both necessary and feasible. In study III, turning points in self-management are illuminated. Turning-point transitions include existential and emotional aspects that increase inner motivation and power
for lifestyle change. Study IV evaluates the effects of a nurse-led intervention in which haemoglobin A1c (HbA1c) was significantly decreased at 12 months’ follow-up. Group intervention and individual intervention were both effective compared to traditional diabetes care.

**Conclusions:** There is a potential for improvement of type 2 diabetes care. Increased patient-centredness is important to support patients towards illness integration and self-management. Focusing on the patients’ illness experiences, including the existential and emotional aspects of having and managing type 2 diabetes, in counselling can lead to improved self-management and glycaemic control. Patients’ experiences of illness are central to their inner motives for change, and patient-centred self-management support and patient education preferably emanate from this perspective.

**Keywords:** Type 2 diabetes, illness integration, turning points, self-management, patient-centredness, diabetes care, primary health care, intervention, randomised controlled study
Swedish abstract

**Bakgrund:** Typ 2 diabetes är en allvarlig sjukdom som ökar globalt. Fokus i diabetesvården har varit att förebygga diabetesrelaterade komplikationer och därmed minska dödligheten. En äldrande befolkning, progression av sjukdomen samt en begränsad förmåga att utföra egenvårdsaktiviteter ökar risken för komplikationer. Grupputfördning och patientcentrerad vård rekommenderas för att förbättra egenvården genom ökad empowerment. Trots dessa rekommendationer har läkare och sjuksköterskor rapporterats vara tveksamma till dessa metoder och hänvisat till bristande kunskap, tidsbrist och avsaknad av verktyg. Att fokusera på patienters sjukdomsinkretiseringsprocess har i litteraturen föreslagits förbättra såväl egenvård som metabol balans.

**Syfte:** Avhandlingens övergripande syfte var att beskriva erfarenheter av sjukdomsinkretisering, sjukdomshantering och support vid typ 2 diabetes samt att utvärdera effekter av en sjuksköterskeledd patientcentrerad modell för egenvårdsupport.

**Metod:** Studierna genomfördes inom primärvården i Västerbottens läns landsting. Totalt deltog 21 diabetessjuksköterskor (Studie I) och 257 patienter (Studie II-IV), i de fyra studierna (Studie II, n=44; Studie III, n= 18; Studie IV, n= 195). Data bestod av fokusgruppsintervjuer (Studie I), individuella halvstrukturerade intervjuer (Studie II-III) och laboratoriemätningar (Studie IV). Analysmetoderna var kvalitativ innehållsanalys (Studie I-III) och statistik (Studie IV).

**Resultat:** Studie I visade att en ideal diabetesvård är svår att uppnå enligt diabetessjuksköterskorna. Paradigmfrågor, maktrelationer och splittrade arbetsuppgifter beskrivs. Studie II beskriver en modell där sjukdomsinkretisering och sjukdomshantering utvecklas samtidigt. När en ”turning point” nåddes såg patienterna sjukdomshantering som både nödvändig och möjlig att genomföra. I studie III belystes ”turning points” och omfattar både existentiella och emotionella aspekter som kan öka inre motivation och egenkraft att utföra livsstilsförändringar. Studie IV
utvärderade 12-månaderseffekterna av en sjuksköterskeledd intervention och HbA1c sänktes signifikant. Gruppintervention och individuell intervention visades vara effektiva metoder i jämförelse med traditionell diabetesvård.

**Slutsatser:** Det finns en förbättringspotential inom diabetesvården och ökad patientcentrerad är viktig för att stödja patienter att integrera sjukdom och egenvård i livet. Att i diabetesvården fokusera på patienters sjukdomsupplevelser inklusive de existentiella och emotionella aspekterna av att leva med och hantera en sjukdom kan innebära förbättrad sjukdomshantering och metabol balans. Patienters sjukdomsupplevelser är centrala för deras inre motiv till förändring och patientcentrerad egenvårdssupport och patientutbildning bör utgå från detta perspektiv.

**Sökord:** Typ 2 diabetes, sjukdomsintegration, “turning points”, sjukdomshantering, patientcentrerad, diabetesvård, primärvård, intervention, randomiserad kontrollerad studie
## Abbreviations and explanations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Explanation</th>
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<tbody>
<tr>
<td>ADA</td>
<td>American Diabetes Association</td>
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<tr>
<td>CSM</td>
<td>Common-sense model</td>
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<td>CVD</td>
<td>Cardiovascular disease</td>
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<td>DSME</td>
<td>Diabetes self-management education</td>
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<td>GP</td>
<td>General practitioner in primary health care</td>
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<td>GT</td>
<td>Grounded theory</td>
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<td>HbA1c</td>
<td>Haemoglobin A1c or glycated haemoglobin test provides information about the average levels of blood glucose over the past 3 months. HbA1c test is the primary test used for diabetes management and diabetes research</td>
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<tr>
<td>HCC</td>
<td>Health care centres</td>
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<td>HCP</td>
<td>Health care professional (nurses and physicians in primary health care)</td>
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<tr>
<td>IDF</td>
<td>International Diabetes Federation</td>
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<tr>
<td>IGT</td>
<td>Impaired glucose tolerance</td>
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<td>IFG</td>
<td>Impaired fasting glucose</td>
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<td>NDR</td>
<td>National Diabetes Register</td>
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<td>QoL</td>
<td>Quality of life</td>
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<tr>
<td>RCT</td>
<td>Randomised controlled trial</td>
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<tr>
<td>SBU</td>
<td>The Swedish Council on Technology Assessment in Health Care [Statens beredning för medicinsk utvärdering]</td>
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<td>T2D</td>
<td>Type 2 diabetes</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Original papers


Background

In my profession as diabetes nurse, I have met many patients with type 2 diabetes (T2D) who, from my perspective managed the disease suboptimally due to insufficient self-management. As a diabetes nurse, it is distressing to meet these patients, since I know that poor self-management will increase their risk of complications later on. Being frustrated over not being able to support all patients in this regard, I have wondered why the self-management is inadequate. I have focused a lot on following routines and checklists for patient visits based upon diabetes guidelines and the National Diabetes Register measures, as I have been taught to do. I realised years ago that to more efficiently support patients in their disease management in daily life, I needed more knowledge and tools to increase their motivation and empowerment. This is something I consider to have been deficient in nurse education but extremely important, particularly in diabetes care. Despite all efforts to lower haemoglobin A1c (HbA1c) levels, with anti-hyperglycaemic agents and support from health care professionals (HCP), only 50% of the patients with T2D remain within the internationally and nationally agreed target levels for blood glucose according to the Swedish National Diabetes Register (NDR) (NDR 2012; Eeg-Olofsson et al. 2010).

This thesis concerns how people succeed in self-managing and integrating a chronic illness such as T2D into their lives, mirrored by interviews and an evaluation of a nurse-led, patient-centred support intervention.

Type 2 diabetes

Type 2 diabetes (T2D) is a metabolic disorder characterised by high blood glucose due to insulin resistance and relative insulin deficiency. T2D is often preceded by prediabetes and metabolic syndrome, risk factors that to-
gether can cause cardiovascular disease and T2D, and it is therefore important to identify and prevent these conditions. Prediabetes consists of impaired glucose tolerance (IGT) and/or impaired fasting glucose (IFG), which means that glucose levels are higher than normal but not high enough to indicate T2D. Prediabetes is often referred to as a preliminary stage of T2D. Metabolic syndrome (Table 1) doubles the risk for cardiovascular disease, and this risk also increases with the number of components included in the syndrome (Alberti et al. 2006; Dekker et al. 2005).

Table 1. Definition of metabolic syndrome NCEP/ATP III (Grundy et al. 2005)

<table>
<thead>
<tr>
<th>Any 3 of 5 constitute a diagnosis of metabolic syndrome:</th>
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<tr>
<td>• Elevated waist circumference &gt; 102 cm in men, &gt; 88 cm in women</td>
</tr>
<tr>
<td>• Elevated S-triglycerides ≥ 1.7 mmol/l</td>
</tr>
<tr>
<td>• HDL cholesterol &lt; 1.03 mmol/l in men and &lt; 1.29 mmol/l in women</td>
</tr>
<tr>
<td>• Elevated blood pressure ≥ 130/≥ 85 mm Hg</td>
</tr>
<tr>
<td>• Elevated fasting-glucose ≥ 5.6 mmol/l</td>
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</table>

In prediabetes, eating habits, physical activity and weight along with heredity are important aspects that influence the risk for development of T2D. The dietary recommendations are reduced fat intake, particularly reduction of saturated fat; reduced fast carbohydrate intake; increased fibre and vegetable intake; and if the person is overweight or obese, reduced calorie intake. The recommended physical activity is 30-40 minutes of moderate activity daily (American Diabetes Association (ADA) 2012; International Diabetes Federation (IDF) 2012; SBU 2010; Swedish National Board of Health and Welfare 2010; Tuomilehto et al. 2001).

T2D is a progressive disease, and the metabolic control tends to become increasingly impaired with diabetes duration, as a result of progressive deterioration of pancreatic β–cell function. Another important factor in T2D is insulin resistance, a decreased ability by muscle and adipose tis-
sues to respond to the effects of insulin, which together with β–cell dys-
function leads to increased blood glucose levels (Bergman 2013).

Diabetes mellitus is increasing rapidly worldwide. In 2011 there were
366 million people with diabetes, and it is estimated that in 2030 more than
500 million people will be affected by diabetes. The largest increase of dia-
etes is in low- and middle-income countries (Whiting et al. 2011). Of all
cases with diabetes, T2D accounts for 85% to 95% (IDF ATLAS 2012).
An ageing population and the fact that approximately 90% of all persons
with T2D are overweight or obese imply that the burden of T2D will in-
crease. The burden is related to complications and suffering for patients
but also to health care systems utilisation and loss of productivity (Haslam
et al. 2005; Whiting et al. 2011).

In Sweden the prevalence of diabetes has been estimated at between
2.5% and 4.5% (n ≈ 350 000) (Östenson 2009). There are likely also a large
number of patients with T2D that are undiagnosed, since it is initially a
hidden disorder. The diagnosis of T2D is defined as raised blood glucose
levels ≥ 7.0 mmol/l, which may occur before patients experience symp-
toms (Rydén et al. 2007; Swedish National Board of Health and Welfare
2010). The onset of diabetes has been estimated to be from 4–7 (Harris et
al. 1992) up to 12 years before clinical diagnosis (Renders et al. 2001). The
risk of T2D increases progressively throughout life. In Sweden the mean
age for diagnosis of T2D is 63 years (Östenson 2009). The mean age for
people cared for type 2 diabetes in primary health care is 68 years (NDR
2012).

**Diabetes-related complications**

Poorly controlled T2D leads to diabetes-related complications, which ac-
count for much of the social and financial burden of diabetes. Therefore, it
is of importance to prevent and reduce suffering and prevent premature
death (ADA 2012). Diabetes complications are also strongly related to de-
creased quality of life (Stratton et al. 2000; UK Prospective Diabetes Study
Group 1998; UK Prospective Diabetes Study Group 1999). At diagnosis the frequency of diabetes-related complications are quite high (Fagan et al. 1998). About 50% of people with T2D already have developed peripheral arterial insufficiency (Prompers et al. 2007), and about 8% neuropathy (Simmons et al. 2002). Furthermore, about 20% have developed diabetic retinopathy (Looker et al. 2012), and up to 17% nephropathy (Agarwal et al. 2011).

Haffner et al. (1998) found that people with diabetes without previous myocardial infarction had the same risk of developing myocardial infarction as people with previous myocardial infarction but without diabetes. People with T2D also have a two- to four-fold greater risk of developing cardiovascular disease (CVD) compared to people without diabetes (Eliasson et al. 2008; Manuel et al. 2004). The risks for CVD increase further with smoking, abnormal blood lipids and high blood pressure (ADA 2012; IDF 2012). Microangiopathy such as nephropathy, retinopathy and neuropathy can occur in T2D, conditions that can lead to renal failure, blindness, impotence and so on. (ADA 2012; IDF 2012). A review by Nalysnyk et al. (2010) found that variability in glucose levels, and especially elevated postprandial glucose (blood glucose level 2 hours after a meal), may result in increased incidence of microvascular complications.

Diabetes is also a global cause of premature mortality (IDF ATLAS 2012). It is estimated that approximately 75%–80% of people living with diabetes die from CVD (Tomilehto et al. 2003). In 2011 4.9 million people died from diabetes; this is 8.2% of the total world mortality in people aged 20 to 79 years. Diabetes is the eight leading cause of death in countries with a high income (IDF ATLAS 2012).

Intensive treatment of diabetes can significantly decrease the development and progression of diabetes-related complications (Gale 2008; Holman et al. 2008). This was first convincingly described in the United Kingdom Prospective Diabetes Study (UKPDS) more than ten years ago (UK Prospective Diabetes Study Group 1998). In other studies, the Action
in Diabetes and Vascular Disease (ADVANCE) trial found the risk for microvascular complications was decreased, but not the incidence of CVD (Patel et al. 2008). The Action to Control Cardiovascular Risk in Diabetes (ACCORD) studies reported that intensive glucose lowering in order to achieve normal HbA1c levels increased the mortality among patients with established CVD. The study was therefore discontinued (Gerstein et al. 2008). From a meta-analysis, Turnbull et al. (2009) stated that intensive glucose control significantly reduced CVD events without reducing cardiovascular or all-cause mortality. It is therefore important to individualise treatment targets, since not everyone—particularly older patients who have an established CVD or other diseases—benefits from an aggressive glucose lowering treatment (Inzucchi et al. 2012). The goal of T2D management is to maintain a near to normal blood sugar level without inducing hypoglycaemia. Metabolic targets that are more stringent should be considered if the patient has short disease duration, long life expectation and only minor complications, and if this can be achieved without frequent hypoglycaemia (Ismail-Beigi et al. 2011). Treatment of all risk factors in metabolic syndrome, including blood pressure, lipids and glycaemia, has a beneficial effect on cardiovascular death in T2D (Adler et al. 2000; Gæde et al. 2008).

**Treatment of diabetes**

The basis for treatment of T2D is lifestyle changes. These are increased physical activity, weight reduction in overweight, smoking sessions and a diet similar to the diet recommended in prediabetes, that is, low and slow carbohydrates with high fibre, whole grains and low-fat dairy products. In most patients, lifestyle changes need to be combined with oral diabetes treatment and/or insulin (Inzucchi et al. 2012; SBU 2010).

Swedish diabetes care adheres to standards outlined in national and international guidelines (ADA 2012; IDF 2012; Swedish National Board of Health and Welfare 2010). In Swedish national guidelines for T2D treatment metformin is recommended as the first choice in oral anti-diabetic
treatment. Metformin increases insulin sensitivity and prevents weight gain. If metformin does not suit the patient due to side effects such as gastrointestinal problems, or is contraindicated or not leading to achievement of treatment goals, sulfonylureas (SU) or insulin should be used. Pioglitazone and acarbose could be used in patients who are intolerant to metformin or SU. A new group of oral anti-diabetic drugs—incretins such as DPP4 inhibitors and GLP analogues—are increasingly used. These drugs influence a natural compound in the body, glucagon-like peptide-1 (GLP1), which helps lower blood glucose (Swedish National Board of Health and Welfare, 2010). In order to recommend effective treatment for individual patients to adhere to, the HCP should consider the perspective from which the recommendations is given, that is, the biomedical or the patients’ perspective.

**Disease, illness and sickness**

By definition, the concept disease traditionally refers to pathological physical processes and diagnoses and can be seen as identifiable deviations from a biological norm that affect organs or systems in the body (Eisenberg 1977). If focus in a consultation only or primarily depends on biological deviations such as blood sugar levels in T2D, it could be regarded as having a disease/ biomedical perspective. Illness, on the other hand, refers to the feelings and experiences of unhealthy, which are entirely personal, interior to the person and sometimes related to a biological state or a disease. Illnesses can have both biomedical and experiential dimensions (Conrad et al. 2010). Pain, discomfort, tiredness, tedium or imprecise feelings that “something” is wrong in the body are examples of illness experiences (Eisenberg 1977). Sickness is the external and public mode of being unhealthy. It is a social role or a status and a position negotiated in the society (Boyd 2000; Eisenberg 1977). Different diseases have various statuses and do not guarantee equality in sickness. Chronic diseases have lower status than acute ones, and psychiatric diseases lower than for example surgical conditions (Conrad et al. 2010). The concepts disease, illness and
sickness are related to each other but also to the concepts health, well-being and satisfaction.

**Health, well-being and satisfaction**

Definitions of health have evolved over time. Early on, they focused on the body’s ability to function, wherein health was seen as a state of normal function that could be disrupted from time to time by disease. A departure from previous definitions was made by the World Health Organization (WHO) in 1948, defining health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” This definition was proposed to more clearly link health to well-being (WHO 1948). Health is nowadays seen more as a process or a movement on a continuum than a state (Antonovsky 1987; WHO 2009). WHO, in the 1986 Ottawa Charter for Health Promotion, pronounced that health is a dynamic resource for living, not the objective of living. The definition of health was revised to include “the extent to which an individual or group is able to realise aspirations and satisfy needs, and to change or cope with the environment” in order to reach physical, mental and social well-being (WHO 2009). Subjective well-being has been viewed as people’s own evaluation of quality of life and consists of a cognitive appraisal of life satisfaction; experiences of positive, pleasant emotions and happiness; and simultaneously low negative mood (Diener et al. 2009). Many researchers nowadays consider well-being as a multi-dimensional construct (Diener et al. 2009), creating a somewhat confusing and contradictory research base. One of the main goals of the St Vincent declaration was to improve the well-being among patients with T2D (Diabetes Care and Research in Europe, 1989). In the area of diabetes, Bradley (1994), in her well-being questionnaire development, has focused on depression, anxiety, positive well-being and energy, which also are seen as important to succeed in self-management and to affect diabetes outcomes positively (Rose et al. 2002).
Patients’ satisfaction is not directly transferable with well-being or treatment satisfaction, since the concept includes many aspects such as disease, treatment, care relations and life satisfaction. Patients with different diseases, ages, gender and ethnicity, from various contexts, have different perspectives on satisfaction and therefore it is difficult to define patient satisfaction, as a homogeneous concept. Patient satisfaction with care represents a mixture of perceived needs, expectations of care and experiences of care (Wilkin et al. 1992). Eriksen (1995) defined patient’s satisfaction with nursing care as a subjective evaluation of and emotional reaction to the expectations of ideal nursing care and the care that is given. Hörnsten et al. (2005a) have described patient satisfaction in diabetes care and reported well-being related to patients and HCPs having the same goals and patients being respected for their decisions. Furthermore, patients describe feelings of well-being when they feel secure and worthy not only as patients or cases but also as persons, and are met with friendly and welcoming attitudes and with respect. Better collaboration between HCPs and patients is reported to be associated with higher well-being and quality of life (Rubin et al. 1999; Göz et al. 2007).

Quality of life (QoL) has been defined as an all-embracing concept about individual’s perceptions of their positions in life in the contexts of culture and value systems and in relation to goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by people’s physical health, psychological state, personal beliefs, social relationships and their relationships to salient features of their environment (WHO 1997). Others state that QoL appears to be one dimension of the multifaceted nature of well-being, seen as a concept that can be used in or in the absence of, illness (Dodge et al. 2012). In the literature, health related QoL has been referred to as psychological well-being, health status and treatment satisfaction, and used together, these aspects can provide detailed insight about the problems with the disease and its treatment that people experience (Speight et al. 2009).
Diabetes and diabetes-related complications are correlated with decreased QoL among patients with T2D (Huang et al. 2007; UK Prospective Diabetes Study Group 1999; Rubin et al. 1999; Wändell 2005). Decreased QoL is also correlated with comprehensive diabetes treatment with multiple insulin injections (Huang et al. 2007), obesity (Svenningsson et al. 2011a,b) and frequent hypoglycaemia events (Amiel et al. 2008). However, events with hypoglycaemia are correlated with lowered general health which may counteract adherence to blood sugar-lowering recommendations (Amiel et al. 2008; Cryer 2008). Suffering and decreased QoL related to living with diabetes, such as psychosocial distress, worries and problems affect people’s abilities to self-manage diabetes (Rubin et al. 1999; Undén et al. 2008). Such problems also influence people’s health–illness transitions.

Health–illness transition

The word transition is increasingly used in nursing literature. Meleis (1991) describes a transition as a change in health status, role relations, expectations or abilities. It denotes changes in needs of all human systems. Health–illness transitions require persons to incorporate new knowledge, to alter behaviour, and therefore to change the definition of themselves in the social context as healthy or not. Such a transition could be defined as “a passage from one fairly stable state to another fairly stable state and it is a process triggered by change” (Meleis 2010).

A review by Kralik et al. (2006) revealed that transitions are ways that people respond to changes over time. When people need to adapt to new situations or circumstances, they undergo a transition in order to incorporate the change event into their lives. Health–illness transitions in self-management have been described by Kralik et al. (2004) as the process an individual undertakes to achieve a sense of balance in living a personally meaningful life and at the same time experience the impact of the disease and its treatment. It is a process of striving for creating order from disorder.
imposed by the illness. This transition does not have to follow a chronological trajectory (Kralik 2002; Paterson et al. 2001). It is rather an ongoing process that may occur in a back and forth manner. Most studies of transitions in living with chronic illness have focused on the process of integrating chronic illness and its management into the person’s everyday life and the person’s inner re-orientation (Kralik et al. 2006; Whittemore et al. 2008).

Living with type 2 diabetes

T2D is a progressive lifelong disease. Patients with diabetes may perceive living with T2D as burdensome, since diabetes balance, that is, well-balanced blood sugars, lipids, blood pressure and so on are hard to reach, and the diabetes needs attention continuously. It demands an adapted lifestyle, influencing physical, psychological and social aspects of daily life. Getting T2D can be seen as a process of integrating illness gradually in daily life, which includes existential, physical and social needs and involves both emotions and cognition (Debo no et al. 2007; Johansson et al. 2009; Telford et al. 2006).

Getting diabetes has been described as becoming another person, with bodily imbalance marked by emotional diversity. This experience is characterised not only by inexplicable, unreal and incomprehensible feelings but also by feelings of relief, when the person gets an explanation of what’s wrong in the body. Existential feelings and insights about life and death can push the person towards an understanding of the situation and its severity (Johansson et al. 2009).

Adapting to and managing diabetes has been expressed as having to balance between sometimes contradictory demands, that is, controlling and being controlled by the diabetes, exercising control by oneself and being controlled by others, accepting oneself as a person with a positive self-image and yet having diabetes. Living with T2D implies to adapting to the
demands of diabetes and at the same time not being ill, developing patterns and also adapting to changes, getting basic but also meaningful knowledge and lastly balancing between not being seen as a troublesome patient and at the same time daring to say what one think to the caregiver (Paterson et al. 1998). People seem to prefer health goals and self-management activities that they believe help them to reach the life goals the disease is threatening (Morrow et al. 2008).

Personal understandings of T2D were studied by Hörnsten et al. (2004) and include views on the image of the disease, views on the meaning of the diagnosis and integration of illness, views on space for the illness and responsibilities for self-management in daily life and lastly views on future prospect with an illness such as T2D. These personal understandings of illness are important aspects to consider and use in counselling, because they influence the activity and the effort put into self-management activities.

**Illness integration**

Integrating a chronic illness takes time. People usually do not change lifestyle due only to insights about a need for change. They need time to negotiate about what these lifestyle changes involve and the consequences of them (Audulv et al. 2009). Illness integration, which in this thesis is chosen as a relevant label, is interpreted as gradually finding a way to live successfully with an illness (cf. Hernandez 1996). It is a phenomenon that has been described by others from various perspectives, that is, philosophy, psychology, pedagogy and nursing. What in this thesis is referred to as illness integration has in the literature been labelled as illness transition (Meleis 2010), exemplars’ experiences (Ellison et al. 1998), expert development (Paterson et al. 2000), learning to live with illness (Kneck 2011) and experiencing meaning in illness (Toombs 1993).

Integration of illness in diabetes is described by Hernandez (1996) as a developmental process that refers to the emotional and existential aspects
of being ill and learning to live with a chronic illness. She labelled this integration as a “science of one”, which is described as the condition when the person’s life and diabetes fit together and when the person takes ownership of diabetes self-management but still focuses on living (Hernandez 1996). This means balancing the demands of treatment recommendations with an individual lifestyle (Hernandez 1996; Whittemore et al. 2002). Whittemore (2005) has described illness integration as a complex person–environment interaction whereby new life experiences are assimilated into the self and activities of daily living such as self-management, resulting in an overall life balance.

Self-management

Self-management and self-care are concepts often used interchangeably. However, in the literature self-care has been defined as the everyday life activities people undertake to maintain life and satisfy needs, such as washing, dressing, eating and interacting with others (Orem 2001), while self-management has been defined as the strategies that people living with illness use in order to live well with an illness (Battersby et al. 2010). Lorig et al. (2003) have stated that self-management is important for people with chronic illness, and only they, themselves can be responsible for their “day-to-day care” and self-management, which is a lifetime task. Funnell et al. (2003, 2004), stated that people with diabetes are self-responsible for the day-to-day decisions related to controlling their disease, in other words self-management. Kralik et al. (2004) refer self-management to the activities people undertake to “create order, discipline and control” in their lives. Some nursing researchers suggest an alternative perspective, that of viewing self-management in illness as the mode people maintain to live well with an illness, such as becoming “successfully ill” (Hörnsten 2004; Johansson et al. 2009; Paterson 2001).

The goal of self-management from a biomedical point of view is to prevent disease-related complications and death by adherence to a pre-
scribed regimen (ADA 2012). Barlow et al. (2002) have defined self-management as the individual’s ability to “manage symptoms, treatment, physical and psychological consequences and life styles changes” inherent in living with a chronic condition. Self-management in diabetes has been described as daily self-management, off-course self-management and preventive self-management. Daily self-management is related to daily diabetes activities, for example administering insulin, taking tablets and exercising, but also staying healthy in general and it consists of three steps. Off-course self-management includes dealing with health problems related to diabetes that may occur for instance blood sugar levels that are too high or too low. Preventive self-management includes activities that people do to prevent health problems such as short- and long-term complications (Moser et al. 2008). Paterson et al. (2002) have analysed how persons with chronic illness acquire expertise in self-managing for example diabetes, HIV/AIDS or multiple sclerosis by learning everyday self-management decision-making. The authors identified the three phases—assuming control, fine-tuning and evaluating self-management. Self-management thus consists of a complex set of processes, which are deeply embedded in every person’s life and is more than learning and complying with treatment regimens (Moser et al. 2008). In this thesis self-management refers to the activities people perform to prevent, monitor and control the T2D in order to live well and reduce the impact of illness in their lives.

Self-management is closely related to efficacy beliefs. Self-efficacy, according to Bandura (1997), is defined as an individual’s belief in his or her own ability to succeed in specific situations, which plays a major role in how challenges such as lifestyle changes are approached. Efficacy beliefs influence how one thinks, feels, motivates oneself and acts upon challenges. Self-efficacy begins to form in early childhood, but continues to evolve throughout life as people acquire new knowledge and experiences. The sources of self-efficacy include mastery experiences and vicarious experiences, that is, seeing people similar to oneself succeed. Furthermore, efficacy beliefs are influenced by social persuasion such as encouragements,
but also by psychological and emotional moods. Lastly, self-efficacy is enhanced by interpretations and misinterpretations of bodily states. Self-efficacy regulates functioning, through cognitive, motivational, affective and selection processes that operate together rather than in isolation (Bandura 1997). A number of contextual factors influence self-management in T2D, and one’s milieu may have both facilitating and constraining effects (Gomersall et al. 2011). Social context affects health and self-management directly and indirectly, since it includes the sociocultural forces that shape people’s day-to-day experiences. Social context concerns historical, political, and legal structures, and processes, organisations and institutions such as health care clinics. It also concerns personal circumstances such as age, gender, family, housing and work, and all these are related to each other (Burke et al. 2009; Gomersall et al. 2011). Therefore, self-efficacy and self-management must be seen in relation to the social contexts of people as individuals.

**Diabetes nursing**

The diabetes nurses’ main task in diabetes care is supporting patients to self-manage the disease and to reach medical goals and well-being. At the primary health care level diabetes care preferably is organised in multidisciplinary diabetes teams with general practitioners (GPs) and diabetes nurses and, if needed, dieticians, physiotherapists and foot therapists (Nilsson et al. 2009). It is also important that the team members define goals for their work that all team members know about, and that all strive to reach. Team-work is recommended, because it has been reported that team work in diabetes care improves glycaemic control significantly (Graber et al. 2002; Goodwin 2011). There is a large variability in responsibilities and organisation of diabetes teams in Sweden and also in the actual county council Västerbotten. The diabetes nurse at a primary health care centre is commonly responsible for coordination of the multidisciplinary
diabetes team meetings and work. The patients, though, are not always obvious members of the diabetes teams. The diabetes nurses are expected to add and share the patients’ perspectives on illness and treatment to the medical perspective, to facilitate care and treatment planning in the diabetes team (Andersson et al. 2009). Sharing patients’ perspectives implies listening to patients’ own motives and goals for self-management which are not always consistent with biomedical goals, but are also important.

Patient-centred care and patient empowerment approaches are emphasized in Swedish diabetes care (Swedish Agency for Health and Care Services Analysis 2012; SBU 2009; Swedish National Board of Health and Welfare 2010). Despite the facts that these approaches are suggested in national and international guidelines, studies on various professionals’ views on the essence of diabetes care reveal that professionals focus primarily on medical treatment and simple information to patients and also expect compliance with regimens (Anderson et al. 2000; Funnell et al. 2003; Holmström et al. 2003; Hörnsten et al. 2011a). It is a complex task for the diabetes nurse to try to unify the goals deriving from the different paradigms of life world knowledge and scientific biomedical knowledge and further to share power and negotiate about expert knowledge (Hörnsten et al. 2008a, 2011a).

Group-based educational programmes directed to people with T2D for training and self-management support are recommended (SBU 2009; Swedish National Board of Health and Welfare 2010). The group leader should be knowledgeable in the area of diabetes but also having competence in health pedagogy and adult learning. Planning, performing and evaluating such self-management programmes have been added to the work tasks of Swedish diabetes nurses.

**Self-management support and patient education**

The purpose of diabetes self-management education is more than providing information to patients; it should also encourage people to maintain a
healthy lifestyle over time (cf. Lorig et al. 2001). It is important to consider
that patients with diabetes often perform 99% or more of the treatment
and self-management themselves and that health care professionals thereby
have a low level of control over how patients treat and self-manage dia-
abetes between visits at the clinics (Funnell et al. 2003). Patients’ goals, pri-
orities, health issues and family demands are therefore of great concern for
enabling nurses and physicians to give appropriate self-management sup-
port (Anderson 1995; Funnell et al. 2012; Hornsten et al. 2004). Further-
more, people’s health status and needs for support may fluctuate over time,
which suggest that self-management support must be seen as an ongoing
process rather than a onetime event (Clark 2008; Paterson 2001). People
furthermore have different beliefs and understandings about the nature and
the causes of the illness, and the impact of illness on their lives (Kleinman
1988; Toombs 1993), complicating self-management support.

Patient education concerns all educational activities directed to
patients. Education and learning are complex concepts and include several
facets and dimensions with cognitive, emotional, psychological, and social
aspects (Deccache et al. 2001). Patient education is an important aspect of
treatment of chronic disease, particularly diabetes (ADA 2012; IDF 2012;
Swedish National Board of Health and Welfare 2010; Weiss 2006). It is,
though, important to consider that knowledge alone most often does not
lead to changed habits (Bodenheimer et al. 2002; Chen et al. 2007). An im-
portant purpose of self-management patient education in T2D is to
strengthen patients’ self-efficacy and thereby facilitate self-management to
improve health status and quality of life among patients (Davis et al. 2008;
(DSME) programmes are increasingly recommended. These educational
programmes have evolved from didactic information delivery to empower-
ment-based programmes. DSME includes not only areas such as the dia-
abetes disease and risks for acute and chronic complications, treatment op-
tions including nutrition and physical exercise, medication, blood glucose
monitoring, but also psychological issues. It has been suggested that DSME
support informed decision-making, self-management and lifestyle changes. Furthermore, DSME is thought to support problem-solving leading to improved clinical outcomes, health status and quality of life and also to prevent acute and chronic complications, thereby decreasing the costs (Funnell et al. 2012; Jarvis et al. 2010).

**Various approaches in self-management support and patient education**

**Compliance and adherence approaches**

Historically, approaches built on patient compliance have been frequently used in health care. In this approach, health care professionals define the problems and give advice about solutions (Funnell et al. 2000), and the patients are expected to follow the HCPs’ advice and instructions (Lutfey et al. 1999). Patients that do not follow the HCPs’ advice have frequently been labelled as non-compliant (Lutfey et al. 1999). Non-compliance, though, is an invalid and not useful construct for understanding the behaviour of patients. The patient is viewed as the source of the problem when adapting to a compliance approach and the solution is that the patient must change and follow the HCPs’ recommendations for lifestyle changes (Anderson et al. 2000). Because of the criticism of the concept of compliance, alternative terms have been developed, for example, adherence, which has been interpreted as a toned-down form of compliance by several researchers (Robinson et al. 2008). On the other hand, other researchers state that adherence represents a broader interpretation and understanding of factors that affect a person’s ability to follow treatment recommendations. The term adherence also has a larger focus on the provider–patient relationship and the patient’s involvement in care, and therefore adherence has been seen as a more patient-centred concept than compliance (Vlasnik et al. 2005).
Patient-centred approaches

Several labels of what I call patient-centred care are identified in the scientific literature. I will therefore use the concept patient-centred in this thesis to discuss the related concepts. Examples of such concepts are individualised, person-centred and client-centred care. There is no international consensus about what patient-centred care is or how it is performed (Swedish Agency for Health and Care Services Analysis 2012). Patient-centred care is said to improve patient outcomes and therefore is a recommended approach internationally. Patient-centred care has also been considered as quite consistent with quality of care. It has been stated not only to improve patient satisfaction with treatment and care but also to reduce health care costs (Bertakiz et al. 2011; Ekman et al. 2012; IDF 2012; Inzucchi et al. 2012; Swedish Agency for Health and Care Services Analysis 2012; Swedish National Board of Health and Welfare 2010). It is furthermore reported that patient-centred care improves communication between patients and HCPs and entails a positive relationship, and thereby increases patients’ trust. Patient-centred care also promotes increased adherence to treatment recommendations (Inzucchi et al. 2012; Stewart 2000).

Patient-centred care is more than a method of communication. It focuses on patients’ preferences, experienced needs and values in decisions about care and treatment. Furthermore, it has a broadened perspective of illness, in which patients’ experiences and control are prominent. It also focuses on interactions, striving for an alliance between patients and professionals working together and having common grounds and goals (Epstein et al. 2005; Glasgow et al. 2008; Mead et al. 2000; Michie et al. 2003; Stewart et al. 2000; Swedish Agency for Health and Care Services Analysis 2012). Howie et al. (2004) reported that patient-centredness in counselling is based on the patients’ concerns, putting emphasis on giving the patients time to express these concerns and also on time and effort to explore patients’ experiences and concerns with open-ended questions.
Despite the reported benefits of patient-centred care, there have been problems implementing it (Adolfsson et al. 2004; Adolfsson et al. 2009; Anderson et al. 2010). In a national survey from 2005 in the United States most of the HCPs described their work as patient-centred, while most patients reported that they had not experienced the care as patient-centred (Robinson et al. 2008). Commonly, HCPs believe their actions are patient-centred but there is not always agreement from the patients’ point of view (Robinson et al. 2008). HCPs have also been reported to have been hesitant to change from traditional consultations to patient-centredness built upon patient empowerment (Adolfsson et al. 2004; Adolfsson 2009; Ponte et al. 2003). Reasons for this hesitation have been reported as not knowing what constitutes patient-centred care, but also perceptions of the approach as more time-consuming and expensive (Bechel et al. 2000; Mead et al. 2000; Radhakrishnan et al. 2012).

Other studies have reported that patient-centred care does not have to be more time-consuming or expensive (Stone 2008). Positive attitudes, kindness, compassion and empathy are aspects of patient-centred care, all of which are completely free. There is a lack of agreement about how to best evaluate patient-centred care in diabetes, and there are request for methods that can evaluate a patient-centred interaction between patients and HCPs (Hudon et al. 2011; Robinson et al. 2008).

**Empowerment approaches**

The word empowerment is related to power, “potere” in Latin meaning “to be able”. The prefix “em” means cause or provide with. The word was introduced in the 1960s in the black power movement, and in the 1970s it was emphasised as a way of improving social welfare (Rappaport 1984; Solomon 1976). Paulo Freire developed a pedagogic approach to enabling empowerment. The aim was that oppressed people would regain control and power over their lives, and thereby the society could be transformed (Freire 2005). Since the 1990s there has been increased attention on em-
powerment and it have been used in for example, management, political science, psychology, social anthropology, teaching and nursing (Clutterbuck et al. 1994; Gibson 1991; Koukkanen et al. 2000; Rinehart 1994; Spreitzer 1996).

Patient empowerment in a health care context is grounded in a striving for equality and respect where the patients’ autonomy is in focus. Patient empowerment promotes individuals’ potential for health and well-being (Gibson 1991; Nyatanga et al. 2002). For empowerment it is important that patients have knowledge and skills and can define and achieve their own goals based on their own values and needs (Funnell et al. 2003; Nyatanga et al. 2002). It is furthermore important that care is planned and performed from this perspective (Ekman et al. 2011; Funnell et al. 2003). Patient empowerment is intended to enable patients to make judgements about their illness and their self-management. When patients select changes by themselves, these changes become meaningful, and the effects of the changes improve over the longer terms compared to cases where HPCs advise patients about what to change (Funnell et al. 2003). Patients’ informed choices and understanding of the consequences of those choices are their responsibilities in an empowerment approach. Self-chosen lifestyle changes must work in the patient’s daily life and also be meaningful and feasible, thereby leading to motivation for lifestyle change over a longer term (Funnell et al. 2003; Funnell et al. 2004). Within an empowerment approach patients are supported to reflect on their experiences of living with diabetes, which may lead to an awareness and deepened understanding of their self-management decisions (Anderson et al. 2010).

The goal of a patient empowerment approach in diabetes care is to prepare patients to make informed choices about their health and also to support their self-efficacy for self-management since higher self-efficacy is related to more effective self-management (Funnell et al. 2003; Funnell et al. 2012; Gatt et al. 2008; Nyatanga et al 2002). The empowerment approach requires that HCPs change from a controlling attitude, feeling re-
sponsible for patients’ self-management decisions. Instead, the HCPs should have a cooperative attitude by which self-management is experienced as meaningful for patients (Anderson et al. 2010). Although empowerment is recommended in diabetes patient education, it seems to be difficult for HCPs to adapt to it (Adolfsson et al. 2004; Anderson et al. 2010).

Effects of self-management support and patient education

To effectively manage T2D and prevent diabetes-related complications, many kinds of self-management programmes have been developed. Despite the existence of a large number of systematic literature reviews and meta-analyses, there is still no consensus about which kind of self-management programme is most effective, either at a population level or from patients’ perspectives (Barbosa et al. 2011). To compare and evaluate the effects of different self-management interventions, the Education Group for Guidelines on Evaluations (1999) stated that all educational programmes should follow these guidelines in order to more easily replicate and describe the interventions. However, I have found it impossible to conclude the literature base concerning self-management programmes and their effects, since they are given a variety of labels deriving from different or mixed scientific paradigms and built on multiple theories. Despite these obstacles, I have, when reading all these reports, found that they all strive for changed habits, lifestyles and behaviour among people with T2D aimed at improving glycaemic control and thereby reducing risks for complications. I will therefore in the literature review below endeavour to describe the interventions according to the authors’ wordings and labelling, when possible.

It has in general been reported that a self-management programme is more effective if it is more intensive (Norris et al. 2002) and has a clear theoretical approach (Sturt et al. 2008; Funnell et al. 2012), it is delivered
face to face (Ellis et al. 2004), and incorporates physical activities (Ellis et al. 2004) and if the persons with diabetes participate and interact actively with the educators (Ellis et al. 2004; Funnell et al. 2012).

The labels of patient education programmes in diabetes are for example, educational or behavioural (Gary et al. 2003; Loveman et al. 2008; Pimouguet et al. 2011; Funnell et al. 2012) psychological (Harvey et al. 2009; Ismail et al. 2004; Steed et al. 2003), psychosocial (Peyrot et al. 2005; Rubin et al. 2006) and social (Göz et al. 2007; Tang et al. 2008; van Dam et al. 2005).

Educational interventions have been reported to influence metabolic control if the programmes are extended in time, include more frequent contact with HCPs. Increasing knowledge among the participants, though, seem to be insufficient to motivate them to effectively self-manage diabetes and therefore does not improve glycaemic control in longer terms (Heisler et al. 2005).

Didactic patient education was evaluated in a systematic review which stated that it was effective only in the short term, but that the effect increased if repetitions and follow-ups were performed. Positive effects were found on diabetes knowledge, self-reported diet and, in short term, on glycaemic control; however effects on improved lifestyle were not found (Norris et al. 2001). Educational programmes over longer intervals were evaluated in a systematic review which stated that more frequent contact between the educator and patients resulted in better glycaemic control (Loveman et al. 2008). The effectiveness of another educational disease-management programme was evaluated in a meta-analysis, and it was reported that such programmes had impact on HbA1c, especially among people with a moderate to high frequency of contact with HCPs (Pimouguet et al. 2011).

A structured educational programme intended to enhance self-efficacy and health-related behaviour was evaluated in a clustered randomised study. The intervention was complex, using a structured manual, work
book, goal setting, stress management and personal consultations. The authors found no effects on glycaemic control at 6 months’ evaluation, but the intervention led to small improvements in diabetes-related distress and confidence in self-management (Sturt et al. 2008). On the other hand, a review concluded that the method the intervention was based on seem to be of less importance; instead, sessions should be compactly grouped together, and not too drawn out in time (Minet et al. 2010).

Psychological interventions have been reported to improve glycaemic control and reduce psychological distress in longer terms however, the kinds of therapies that work are unclear (Ismail et al. 2004).

Reduction of psychosocial barriers for effective diabetes management was evaluated in the DAWN study (Diabetes, Attitudes, Wishes and Needs). Poor self-management was associated with psychological burden, which was prevalent long time after diagnosis. Fear of complications resulted in social disabilities and psychological burdens. Providers reported that the majority, 41% of their patients with T2D experienced psychological burden but only 12% received psychological treatment. Better collaboration between the patient and the HCP was associated with increased metabolic control, self-management and well-being (Skovlund et al. 2005, Peyrot et al. 2005; Rubin et al. 2006). A meta-analysis (Cochran et al. 2008) evaluating the influence of diabetes self-management training on quality of life reported improved QoL among the participants.

Social interventions were evaluated in a systematic review of controlled studies, and it was stated that they positively affected glycaemic control, self-management and reduced psychological distress (Göz et al. 2007; van Dam et al. 2005). Social support refers to the interactions that occur in social relationships and how people evaluate these interactions in terms of supportiveness. Peers, families, neighbours, colleagues and so on play important roles in these interventions (van Dam et al. 2005). An observational study including a social intervention among African-
Americans reported positive effects on glycaemic control, quality of life and self-management (Tang et al. 2008).

A non-didactic self-management programme focusing on figuring out own risk factors and individual goal setting was evaluated in a controlled study based on the DESMOND (Diabetes Education and Self-management for Ongoing and Newly Diagnosed) study. The curriculum that was used, focused on lifestyle factors such as food choices, physical activities and cardiovascular risk factors. The patient-centred intervention did not result in improvements in glycaemic control at the 12 months’ evaluation, but in greater understanding of the illness and its seriousness. Furthermore, it resulted in improved weight loss and smoking cessation compared to those attending regular care (Davies et al. 2008). At 3-year follow-up the non-smoking and weight loss seen at the 12-month evaluation were not sustained, but the illness beliefs persisted, indicating that the participants agreed that T2D is a chronic illness that needs management and responsibility. One conclusion was that there is a need for an ongoing support from HCPs to sustain benefits from self-management programmes (Khunti et al. 2012).

Studies of internet-based interventions or mobile phone messaging to promote self-management have reported various effects on changed health behaviour and metabolic changes in diabetes and other chronic illnesses, where some interventions had small or negative effects (de Jongh et al. 2012; Glasgow et al. 2012; Webb et al. 2010), and others reported large effects on glycaemic control and improvement in physical activity (Hurling et al. 2007; Kim et al. 2006).

Group-based educational interventions have in systematic reviews resulted in significantly improved glycaemic control (Loveman et al. 2008; Deakin et al. 2005). Hörnsten et al. (2005b, 2008b), in a randomised controlled intervention study, found positive effects on glycaemic control of a patient-centred group support. Heinrich et al. (2010) reported in a systematic literature review that group interventions and interventions using a
collaborative approach had the greatest potential to improve glycaemic control and knowledge. Despite national recommendations on group education in favour of individual patient education in T2D, both individual and group approaches in diabetes education have been reported effective in some studies (Clark 2008; Duke et al. 2009; Rickheim et al. 2002). Sperl-Hillen et al. (2011) found even greater improvement in HbA1c levels from individual intervention than group intervention.

Problem-based learning group education in T2D has in an RCT study been demonstrated significantly decrease HbA1c levels at 6-months and 24-months follow-ups. The exact difference in HbA1c between intervention and control is not outlined in the article. The initial educational programme included a video, dice game, teaching booklet and diary. Monthly follow-up sessions were led by trained pharmacists and nurse specialists. The guiding pedagogical principle for the follow-up sessions was that questions raised by the group, members should be solved by the group rather than the group leaders (Sarkadi et al. 2004).

Patient-centred approaches have demonstrated positive outcomes in glycaemic control. Hörnsten et al. (2008b) reported positive results on glycaemic control from a programme focusing on patients’ personal understandings of illness, aimed at supporting patient empowerment. Several studies have reported that a patient-centred approach increases chances of improving habits among patients with various chronic diseases and also that patient-centred care is associated with decreased utilisation of health care services and lower costs (Bertakis et al. 2011; Ekman et al. 2012). Randomised controlled trials of patient-centred care in diabetes in general practice have demonstrated positive effect on patients’ quality of life, well-being and treatment satisfaction, without loss of glycaemic control. Patient-centred care furthermore improved self-management, treatment adherence and disease control and also communication between patients and HCPs (Coulter 2012; Haynes et al. 2008; Kinmonth et al. 1998; Renders et al. 2001). On the other hand, tailored interventions, defined as customised to
the individual’s needs, abilities and preferences, which can be seen as a subset of patient-centred or patient empowerment approaches have been reported as having had no impact on self-management activities and only modestly improving dietary fat intake and levels of physical activity in T2D (Radhakrishnan et al. 2012).

In summary, previous (Norris et al. 2002; van Dam et al. 2005; Steed et al. 2003), as well as current reviews (Minet et al 2010; Pimuouget et al. 2011), have stated that small to moderate effects on metabolic improvement could be reached in shorter terms with self-management support. The mentioned results from interventions have been performed in study forms. Fully implemented interventions in clinical practice have seldom been presented. The methods and interventions that effectively support self-management in T2D are still quite unclear (Coster et al. 2009), even if patient-centred and empowerment approaches are advocated. These two approaches and problem-based learning seem to be promising.

**Rational for the thesis**

Despite efforts to lower HbA1c levels, with anti hyperglycaemic agents and support from health care professionals, many patients with T2D remain above the agreed international and national target levels for blood glucose (Monnier et al. 2008), increasing the risks for diabetes complications and mortality. T2D is initially a silent disease, and patients may not experience any symptoms or problems from the disease in an early stage. The insights into the severity and risks of T2D are thereby often disregarded by patients, since it is complications that decrease patients’ quality of life (UK Prospective Diabetes Study Group 1999). Globally, T2D is increasing rapidly and effective support for self-management is demanded to reduce suffering, care utilisation and costs. Literature reviews and meta-analyses on effects of self-management interventions are, though divergent. Patient-centred care and group education are increasingly recommended in diabetes
care, despite HCPs’ hesitations about patient-centred approaches aimed to strengthen patient empowerment. Since HCPs still frequently use traditional approaches in diabetes patient education, it is of importance to understand their views on effective care and support of self-management. To more effectively support patients in self-managing T2D, we also need a deeper understanding of how they integrate illness in daily life and how they relate their self-management to their future life. Swedish medical authorities have demanded increased patient-centredness in health care and also have demanded research programmes evaluating the effects on HbA1c among patients with T2D. However, since the literature is divergent about effects of self-management support and patient-centred interventions, we need more knowledge about which interventions are most effective for improving patients’ self-management and metabolic balance.
Aims

The overall aim of the thesis was to describe the experiences of illness integration, self-management and support in type 2 diabetes and to evaluate the metabolic effects of a nurse-led patient-centred model for self-management support.

**Study I:** To describe conditions for “good care” in type 2-diabetes care as perceived by diabetes specialty nurses.

**Study II:** To describe the process of illness integration and self-management among people with type 2 diabetes.

**Study III:** To illuminate turning points in self-management in type 2 diabetes.

**Study IV:** To evaluate effects on metabolic changes of a patient-centred intervention in type 2 diabetes.
Methods

Theoretical framework

The thesis relies on patients’ personal understanding of illness (Hornsten et al. 2004), which has roots in theories about patients’ illness perspectives and common-sense models of illness (Kleinman 1988; Cohen et al. 1994; Leventhal et al. 2003). Understanding peoples lay views of an illness in order to understand motives for change is essential. Leventhal and colleagues developed the common-sense model of self-regulation of health and illness in the 1980s in order to understand individuals’ illness perception, and their ability and intention to perform self-management. The theory has had various designations, such as the self regulation theory, the common-sense model of illness representation and Leventhal’s theory (Diefenbach et al. 1996; Leventhal et al. 1997; Leventhal et al 2003; Hale et al. 2007). For ease of communication the theory will be referred to as the common-sense model (CSM) in this thesis. Self-regulation concerns the processing of information by a patient regarding health and the self-management necessary to gain control over the disease or return to a normal state of health. A symptom of an illness or a diagnosis starts a cycle of self-regulation.

Lay beliefs about illness concern five dimensions according to the CSM, and they are cause, identity or labelling, timeline, consequences and controllability. Cause is defined as the individual’s own ideas about the perceived cause of the illness. Identity is defined as the lay perception, the label or name of the illness and perceived symptoms. Timeline is defined as beliefs about when the condition started, how long it will last, whether the illness is acute, chronic or fluctuating and the future progression of the illness. Consequences are defined as individual beliefs about the consequences of illness, not only the perceived seriousness or severity but also the impact on life, both physically and socially. Control is defined as the
beliefs about cure or control, including the role of self-management (Leventhal et al. 1997).

Since people experience illness in various ways, and also may perceive a range of problems that are pertinent only to the individual, they make sense and respond to these problems by creating personal models or perceptions of their illness. A person’s illness representations are a network of related information and perceptions, for example memories, ideas, attitudes and beliefs about the health problem. These perceptions are fundamental, because they form the framework in which all new information is evaluated and understood, and thereby they influence people’s self-management behaviour. If health is disrupted by illness or risk, a person may become motivated to regain the balance in life, for example, by self-management (Leventhal et al. 1997). Using the CSM in self-management support and figuring out patients’ beliefs about illness is consistent with patient-centred care and could be seen as a gateway to influencing and improving patients’ outcome (Donovan et al. 2007).

**Methodological assumptions**

In this thesis I have combined qualitative and quantitative methods. In order to describe and explore experiences of diabetes nursing care, illness integration and turning points in T2D, a qualitative approach has been used (Studies I–III). For these studies I have used interviews to acquire knowledge of the subject’s experiences of giving care and living with T2D. To evaluate effects on metabolic measurements from a patient-centred intervention, a quantitative approach has been used (Study IV) (Polit et al. 2012; Sandelowski 2000).

There three assumptions that underlie research, the ontological, the epistemological, and the methodological (Polit et al. 2012). In Table 2 these assumptions are related to qualitative and quantitative research.
Ontological assumptions concern the nature of the world and human beings in social contexts, which can be seen in various ways. The ontology is important when we interpret the findings in our research. In qualitative research (Studies I–III) it is emphasised that the world has various meanings that change according to the social contexts. As a result, qualitative research may have different interpretations of one observation, and the finding is often seen as a result of a co-creative process between the researcher and the research subject, and thereby could be described as subjective. In descriptions of the ontology in quantitative research (Study IV) it is often emphasised that the research phenomenon is independent and there is only one objective truth (Polit et al. 2012).

Epistemological assumptions refer to the ways we acquire knowledge and are important to consider when deciding designs in research. In qualitative research (Studies I–III) based on relativism, we try to describe and understand various phenomena inductively, and they could be studied in a number of ways, since they are related to the context of the phenomena. Results are seen as context related, and the trustworthiness is strengthened by thorough description of the research process to facilitate the transferability of results to other contexts. In quantitative research based on realism (Study IV), we try to explain various phenomena deductively, where hypotheses are tested to be accepted or not, telling us the “truth”. Results are seen as generalisable and should be possible for other researchers to replicate (Polit et al. 2012).

Methodological assumptions finally, refer to the methods used for obtaining the data. In qualitative research, data such as interviews (Studies I–III), observations, field notes and so on are collected. Various qualitative analysis methods can be used, and the findings can be open to many interpretations. Which method is used depends on the researcher, the research questions, the phenomena studied and the contexts (Polit et al. 2012; Sandelowski 2000). A qualitative analysis does not attempt to quantify, since the intention is to describe and understand a phenomenon. What one
person says in a qualitative interview is as important as what many people say. The intention is to highlight as many nuances as possible of a phenomenon (Sandelowski 1996). In quantitative research quantitative data is collected, and statistical analyses methods are used to test hypotheses. Statistical methods are mathematic calculations used to generalise findings from a smaller sample and to control validity and reliability. Statistical results need power, that is, enough participants to become statistically significant (Polit et al. 2012).

Table 2. The qualitative and quantitative approaches used in thesis; their assumptions and their keywords (cf. Morgan 2007; Polit et al. 2012; Sandelowski 2000)

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</tr>
<tr>
<td></td>
<td>Context related</td>
<td>Generalisation</td>
</tr>
<tr>
<td><strong>Methodology</strong></td>
<td>Qualitative data</td>
<td>Quantitative data</td>
</tr>
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<td></td>
<td>Individual interviews</td>
<td>Laboratory measurements</td>
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<td></td>
<td>Focus group interviews</td>
<td></td>
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<tr>
<td></td>
<td>Qualitative content</td>
<td>Statistical analysis</td>
</tr>
<tr>
<td></td>
<td>analysis</td>
<td>Validity and reliability</td>
</tr>
<tr>
<td></td>
<td>Trustworthiness</td>
<td></td>
</tr>
</tbody>
</table>

**Design**

Studies I–III have a descriptive qualitative design based on interviews with diabetes nurses and patients with T2D. Study IV is a prospective randomised controlled study with a quantitative design evaluating a patient-centred intervention (Table 3).
Settings

The study was in the main performed in primary health care in the County Council of Västerbotten in northern Sweden. Study I was performed within 17 primary health care centres in Västerbotten and Västernorrland. Study II was performed within Umeå primary health care, where four health care centres (HCCs) located in both rural and urban areas participated in the study. In study III and IV executive managers from 19 HCCs were informed about the study and nine HCCs accepted inclusion. Private HCCs were excluded because of practical issues such as not having the same data records. At the time of the sampling process only two HCCs were privately owned, and some HCCs were merged during the study period. An external control group was recruited from an adjacent county, Västernorrland.

Sample and randomisation

Eligible patients in the studies (Studies II–IV) were identified by the computerised patient record system at each HCC. Inclusion criteria were being diagnosed with T2D within two (Studies II, III) or three (Study IV) years, aged 40–80 years, Swedish speaking, having no other severe illness or cognitive impairment and being registered at a County Council–based HCC. Patients meeting the inclusion criteria were contacted by letter with information about the study. They were offered the opportunity to participate and asked to respond using a pre-paid reply letter. The participants who volunteered for the study were later contacted by telephone by a member of the research team to schedule the time and place for an interview (Studies II–III).

In study I, a convenient sample of diabetes nurses (n = 21) (19 women, 2 men) from 17 HCCs in Västerbotten and Västernorrland participated. They were contacted either by their executive managers or through a
coordinating diabetes nurse and informed about the study by telephone or in person.

In study II, a randomised sample of patients (n = 44) (21 women, 23 men) included in an intervention group in a previous intervention study from four HCCs located in rural and urban areas in Västerbotten participated. The mean age of the participants was 64 years (range 47–80). They were contacted by letter and were asked to participate in a group support intervention (reported elsewhere) and to participate in an initial interview.

In study III, a convenient sample of patients (n = 18) (8 women, 10 men) who had volunteered in the diabetes intervention in Västerbotten (DIVA 2) were invited to participate. To get a maximum varied sample, age, gender, and duration of diabetes were taken into consideration (Sandelowski 1995). Mean age of the participants was 52 years (range 40–79). The participants were invited by letter and informed by telephone about the interviews.

In study IV, a randomized sample of patients (n = 195) (73 women, 122 men) from nine HCCs in Västerbotten and one HCC in Västernorrland were included. The participants from Västerbotten were identified though the electronic patient record system and randomised to either group intervention (GI), individual intervention (II) or an internal control group (IC) (Figure 1). In order to control for spill over effects, an external control group (EC) was recruited from one HCC in Västernorrland (n = 174). Mean age of the participants was 64.5 years (range 40–80). The procedure of the randomisation process was as follows. The participants from Västerbotten were first randomised to one of three groups (GI, II, IC) and then randomly numbered on a list and consecutively invited to participate. This was done to create appropriate group sizes at HCC level. The sample size was chosen based on a power calculation whereby a difference between groups of 1% (approximately 5 mmol/mol) in HbA1c and a power of 0.8 demanded at least 33 participants in each group. The participants from Västernorrland (EC) were recruited with the same inclusion criteria and a
similar process for random inclusion. The participants that were randomised but not offered participation were not contacted. The diabetes nurses (n = 10) from the nine HCCs in Västerbotten participated and led the patient interventions (Study IV).

Procedure and interventions

Before the intervention started, the participating diabetes nurses received theoretical and practical preparation in patient-centred support, illness/disease perspectives and motivating patient-centred dialogues aimed at strengthening patients’ self-efficacy for self-management. Ambivalence and resistance as well as possibilities for self-management were discussed in role-plays, where the nurses had opportunities to reflect upon patients’ personal understandings of illness and its relatedness to self-management. Furthermore, patients’ and nurses’ different perspectives of illness were reflected upon as an important aspect to be aware of in communication about self-management. This preparation required approximately 20 hours.

Patient intervention

All patients received their regular check-ups with their regular physicians and nurses, which, according to the local T2D-programme, includes one encounter with a physician each year and one with a diabetes nurse, preferably organised semi-annually.
Beyond the regular check-ups, the intervention consisted of support sessions in groups or individually, organised as six sessions over approximately 6–9 months. The 1- to 1.5-hour sessions were intended to be patient-centred and focused on personal understandings of diabetes (Hornsten et al. 2004). Patients were free and encouraged to discuss eve-
everything they wanted, but each session also included one of the six themes: views on the image of the disease, the meaning of the diagnosis, the integration of illness, the space for self-management, responsibilities for self-management and, lastly, the future prospects with T2D. In the group intervention the diabetes nurses acted as moderators and made sure that everyone in the group participated in the conversation about the theme for the meeting. Traditional diabetes knowledge and medical facts were conveyed only when requested. After the six sessions ended, the participants in the intervention groups received short telephone follow-ups each month for half a year.

**Data collection**

Qualitative and quantitative data were collected. Three focus group interviews (Study I) were performed with an interviewer and an observer. Focus group data were collected in 2009 at an HCC or at a conference centre. The interviews lasted between 50 and 90 minutes and were recorded and transcribed verbatim by LJ.

Forty-four individual, semi-structured interviews (Study II) were performed in 2001 by the main supervisor, ÅH. The interviews lasted between 30 and 90 minutes and were recorded and transcribed verbatim by ÅH. This study concerns a secondary analysis of data collected earlier by ÅH (Hornsten et al. 2004).

Eighteen individual semi-structured interviews (Study III) were performed at baseline of study IV. The baseline interviews lasted between 30 and 90 minutes and were recorded and transcribed verbatim by LJ.

Laboratory- and physical measurements (Study IV) for this thesis were collected at baseline and at one-year follow-up. An overview of methods used during data collection and analysis is presented in Table 3.
Table 3. Overview of studies, participants and methods

<table>
<thead>
<tr>
<th>Studies and status</th>
<th>Participants (n)</th>
<th>Data collection</th>
<th>Period for data collection</th>
<th>Analysis</th>
<th>Design</th>
</tr>
</thead>
<tbody>
<tr>
<td>I Published</td>
<td>21 nurses</td>
<td>Semi-structured focus group interviews</td>
<td>2009</td>
<td>Qualitative content analysis</td>
<td>Qualitative</td>
</tr>
<tr>
<td>II Published</td>
<td>44 patients</td>
<td>Narrative interviews</td>
<td>2001</td>
<td>Qualitative content analysis</td>
<td>Qualitative</td>
</tr>
<tr>
<td>III Published</td>
<td>18 patients</td>
<td>Semi-structured interviews</td>
<td>2010</td>
<td>Qualitative content analysis</td>
<td>Qualitative</td>
</tr>
</tbody>
</table>

**Interviews**

**Focus group interviews**

In study I, focus group interviews were conducted in which the area of interest initially was introduced with an open-ended question about what the participants, from their primary health care perspective, perceived as conditions for “good” care in T2D. The participants were asked to give examples of occasions when they felt that they had succeeded in offering quality care and when they felt they had failed. The participants were interviewed in three groups of six to eight participants, and this group size was estimated as small enough to maximise discussion yet still maintain order (Peek et al. 2009). During the interviews, the role of the interviewer (LJ) was to moderate the interviewees to maintain focus, to inspire broader or deeper answers by probing, and to support all interviewees in co-operating and reflecting upon the questions. When divergent opinions were obvious, the participants were asked by the moderator (LJ) to clarify their thoughts.
for further discussion and reflection. An observer participated (ÅH) and kept mind notes of the content of the interview, which were reviewed within the group before finishing the interview (Kylmä et al. 2007). The interviews took place at either an HCC or a conference centre and lasted between 50 and 90 minutes.

**Semi-structured/narrative interviews**

The overarching purpose of the patient interviews was to elucidate illness experiences and the process of integrating the illness and coping with the demands related to living with diabetes, such as self-management (Studies II, III). The interviews were conducted an interactive fashion, and thereby the interviewer is a co-creator of the text (Mishler 1986).

Semi-structure interviews (Study II) of a narrative character were conducted by ÅH and consisted of open-ended questions intended to uncover the participants’ understanding of T2D and how their experiences changed as they lived with the illness. The participants were encouraged to talk freely about their experiences. Illness narratives, according to Kvale (1996), give voice to both the suffering and the life world context of illness, and a qualitative interview as such is a specific form of conversation aimed at understanding dimensions of the interviewee’s life world.

Semi-structured interviews (Study III) with patients living with T2D were conducted by LJ. Open-ended questions were used to describe the illness integration leading to a turning point in self-management, or not. The answers were followed by probing questions like, tell me more about that; can you describe more; and, how do you feel about that, in order to gain further reflections and emotional descriptions about the problem. The interviews lasted from 40 to 90 minutes and covered themes about developing diabetes, coping with diabetes and living with diabetes.
Laboratory and physical measurements

Haemoglobin A1c (HbA1c), total cholesterol, high-density lipoprotein (HDL), low-density lipoprotein (LDL) and triglycerides (TG) were measured with standard clinical laboratory methods. Blood pressure (BP) was taken manually by trained nurses, in the right arm with the patient in a sitting position after a minimum of 5 minutes rest. Weight was measured and BMI calculated as weight (kg)/height (m)^2.

Analysis

Qualitative content analysis

Content analysis has historically been used as a method to analyse texts in both qualitative and quantitative manner (Graneheim et al. 2004). In this thesis (Studies I–III) I have used qualitative content analysis (Krippendorff 2004; Graneheim et al. 2004). The analysis was performed in several steps. First, the interview text was transcribed verbatim by LJ, and read several times and discussed in the research group to gain a basic understanding of the content. Thereafter, meaning units corresponding to the aim were identified and condensed, that is, shortened, while still preserving the core. The condensed meaning units were labelled with codes that described the content. The codes were then sorted into tentative categories based upon common denominators or deviances between the codes. Finally, each subcategory and category was critically read and analysed and themes were formulated. A theme is a thread of meaning running through categories on an interpretive level (Graneheim et al. 2004). In the article describing study II, which is a secondary analysis, the analysis was stated to have been inspired by Grounded Theory (GT), since the aim was to explore a process. However, as the interview questions were originally formulated to identify and describe a process in a timeline, the research group has since decided that this analytic process follows the qualitative content analytic method.
and could be seen as a development of this qualitative method. The sample was also decided upon on forehand, due to the intervention and randomised design of the study, which strengthen this decision. In study II, the text about the illness integration process was identified as constituting the unit of analysis. The text was read several times to understand the general content and discussed in the research group. Thereafter, the meaning units corresponding to the aim were identified, condensed and coded. Notes and ideas about relationships between categories were also written down to make it possible to discuss and compare data and to explore ideas about the relationships between the preliminary codes and categories. To strengthen the credibility of the analysis and its results, a constant comparative method was used, with a back and forth movement from the interpretations to the original individual interviews to verify the interpretations of relationships between categories. A preliminary model/mindmap of our categorised data was developed, in which categories sometimes were modified or moved and themes identified, however always validated by comparisons with the original texts (cf. Charmaz, 2006). To enhance trustworthiness, codes, categories and themes were discussed and reflected upon throughout the analytic process (Graneheim et al. 2004).

Statistics

A power calculation was performed to estimate the sample size for each group in the intervention study (Study IV). The statistical analyses in study IV were carried out with the statistical software SPSS for Windows. To explore differences between groups, one-way ANOVA, Chi-square and Fisher’s exact test were used. An ANCOVA was conducted in order to adjust for differences between the groups at baseline. Paired sample t-test was used to explore the differences between baseline and follow-up. P-values <0.05 were considered as statistically significant (Field 2009).
Ethical considerations

Studies I–IV were approved by the head of primary health care, health care managers at each HCC and the Ethics Committee of the Faculty of Medicine (Dno 00-323) (Study II), and the Regional Ethical Review Board in Umeå (Dno 06-126M) (Studies I, III–IV). The participants in the studies were informed in writing about the studies, and were told that participation was voluntary, and that they could drop out of the study without giving any reason. Oral (Study I) or written (Studies II–IV) consent was obtained for the studies. The participants were guaranteed confidentiality, and the results are presented at group level to avoid identification. Quotations have been de-identified (Krueger 1994). The research group was prepared to meet and handle emotional reactions as a consequence of the interviews, but no person asked for such help. Risks were seen as low, and the benefits, with a possibility to improve care for this group of people, important. Many participants in the interview studies expressed gratitude and were positively surprised that someone was interested in listening to their stories.

Results

Experiences of diabetes self-management support

Study I aimed to describe diabetes nurses’ perspectives on “good care” in T2D care. The findings in this study demonstrated that achieving ideal conditions for “good” diabetes care was complex. Conflicting paradigms, power relations and departmentalisation of work influenced the potential for nurses to deliver “good” diabetes care. The analysis resulted in following four themes: Diabetes counselling built on empowerment versus governance, Diabetes management built on comprehensive versus biomedical
views, Diabetes care organisation built on nurse-led versus physician-led care, and Diabetes care organisation built on quality versus equality.

In the first theme, diabetes nurses’ counselling was described as governing among those patients that were seen as non-compliant. Patients who were active in their self-management, adherent and aware of their own responsibility for disease management were an ideal. The nurses’ responsibility was to inform and support them to improve their lifestyles, to manage self-tests and to comply with treatment recommendations. Patients who did not take enough responsibility for self-management were perceived as hard to handle and needing governance. The nurses experienced a lack of tools and knowledge to effectively counsel these non-compliant patients.

In the second theme, the diabetes nurses emphasised that they were engaged, skilled and up to date in diabetes care. They also said that they had a comprehensive view of patients, were patient-centred and acknowledged the patients’ experiences of living with diabetes. They tried to build trust and increase the patients’ confidence in them. However, the nurses also expressed that they mainly focused on biomedical measurements and metabolic balance and viewed targets for treatment and metabolic measurements as most essential in diabetes care.

In the third theme, the diabetes nurses requested an effective organisation of diabetes care. Shortage of General Practitioners (GPs) implied that the diabetes nurses had to manage almost everything. Nurse-led care was seen as a benefit, to maintain continuity and regularity, treatment evaluation and quality registration in the NDR. Despite this, the diabetes nurses reported that the care was physician-led, since it was the physicians who prescribed medication and made final decisions about the treatment. However, the nurses expressed that many GPs needed to update their diabetes knowledge and used outdated treatment targets. The nurses requested more collaboration with GPs to discuss treatment options and prescriptions.
In the fourth theme, the diabetes nurses described the diabetes care as being organised more on the basis of equality than quality. Offering annual appointments irrespective of actual needs was one example of striving for equality not quality, since the accessibility should be adapted to patients’ needs. Not enough time and resources were allotted for sufficient quality if care. Ideally, patients should have the opportunity to get their questions answered the same day, which the nurses were not able to do. They focused mostly on newly diagnosed patients and those with insulin treatment, while the resources devoted to self-management support of patients over time were minimised. The use of quality registration and evaluation were seen as important to improve quality of care, even if the NDR had limitations and only evaluated biomedical issues.

**Illness integration**

Study II aimed to describe the process of illness integration and self-management in T2D.

The findings in this study revealed that illness integration and self-management in general run in parallel. When a turning point is reached, the disease and its management become a part of the person’s everyday life. This may happen when a person accepts the illness emotionally, existentially and in practice. This process is represented in the schematic figure below (Figure 2). The process includes three process-elements within the blue circle that have been labelled “Suspecting illness and/or being diagnosed”, “Understanding and explaining illness”, and “Negotiating illness and taking stands about self-management”. These process-elements commonly appear in this particular order, but for a few patients they can appear simultaneously.

Suspecting illness and/or being diagnosed, the stage where the illness integration process is started, includes being diagnosed and sometimes perceiving bodily sensations or symptoms. Some patients experienced a relief
that it was “only” diabetes; they had suspected a more threatening disease, while other considered diabetes as a chaotic experience.

Figure 2. A model of integration of illness and self-management in type 2 diabetes.

Understanding and explaining illness, the second stage, included trying to understand T2D in terms of not only causes and illness severity but also its impact on daily life. Participants attributed the reasons for developing diabetes were to internal factors such as not eating well, not exercising enough and gaining weight, and also to external factors such as having a busy job, having a genetic predisposition and viewing diabetes as something normal, that comes with ageing.
Negotiating illness and taking stands about self-management, the third stage concerns balancing and taking stands about self-management activities that possibly may increase well-being on the one hand but also decrease wellbeing by burdening daily life.

The illness integration process is encompassed circumstances that are, perceiving and taking stands about the seriousness and threat of the disease, responding emotionally, viewing the disease as fitting in with personal goals and expectations and lastly, evaluating outcomes and impacts of self-management.

Some patients perceived a low impact of the disease on daily life, while others perceived a high existential threat due to shame or worries about future complications. We interpreted that experiencing a moderate threat had the greatest influence on self-management. The perceived emotional responses were strongly related to the perceived seriousness and threat of the disease. The disease and self-management activities were related to the personal goals and expectations of patients and concerned views about the present and the future. If the disease and the self-management activities fit in with the person’s life they could easily be integrated. The perceived outcomes and impacts of self-management influenced the illness integration process. If self-management activities lowered blood glucose and increased well-being, it motivated patients to continue.

A turning point was passed when patients integrated the illness emotionally and existentially, and in practice, by their self-management. The turning point was experienced as a sudden occurrence of a need to act and also a personal responsibility. After reaching a turning point when life and illness go hand in hand for a shorter or longer period, new problems or issues, such as diabetes-related complications, may appear, prompting a return to the integration process.
Turning points in self-management

Study III aimed to illuminate turning points in self-management in T2D more deeply. The analysis revealed that turning points in self-management include four important insights: being in a life and death struggle; being at a crossroads with no return; being the one who decides, and lastly, being the one who can change the outcome. Being in a life and death struggle was described as an insight that the illness had become more serious than before. Feeling that it was too early to die and not being able to deny it anymore were described, and therefore the illness demanded management in one or another way. Being at a crossroads with no return was described as an insight into not being able to postpone the disease management any longer. The participants revealed that they had to effect a hasty change in behaviour in order to avoid complications and other threats of the disease. This change was seen as essential and immediate, and they had reached a point where they believed that it was now or never. They had also reached a point of no return when they realised the consequences for them if complications were to occur. Being the one who decides reflected the patients’ awareness that it was only they themselves who could decide whether they should make any lifestyle changes. They reported that they had realised that their motives and willpower for changed behaviour must come from themselves, not from anyone else. Being the one who can change the outcome was described when the participants realised that they really could change the outcome and also that they had the power and knowledge to do it. It also concerned finding own ways to improve self-management and to evaluate the effects of the actions.

Evaluation of a patient-centred intervention

Study IV aimed to evaluate the effects on metabolic changes from a nurse-led patient-centred intervention in T2D. In total, 182 participants took part
in the intervention designed as an RCT. Patients were allocated to group intervention (GI) (n = 63, women n = 20, men = 43), individual intervention (II) (n = 34, women n = 13, men = 21) internal control group (IC) (n = 34, female n = 16, male = 18) and external control group (EC) (n = 51, women n = 19, men = 32) (Table 4). The mean attendance rate was 79.4% in the GI group, compared with 95.8% in the II group. No significant differences were found in age, gender, BMI, waist circumference or blood pressure between groups (GI, II, IC, EC) at baseline. An ANCOVA with post hoc test at baseline showed a significant difference in HbA1c between the GI (IFCC 52 mmol/mol or Mono-S 6.0%) and EC groups (IFCC 47 mmol/mol or Mono-S 5.5 %, p = 0.020), and a difference in total cholesterol between the GI (4.63 mmol/mol) and EC group (5.38 mmol/mol, p = 0.007). There was also a significant difference in treatment (p = 0.037), where the EC group proportional had more insulin treatment (17.6%) compared to the GI group (1.5%), II group (3.0%) and IC group (8.8%) (Table 5).

The result in study IV showed that HbA1c levels changed within groups and decreased from baseline to 12-month follow-up in both the GI (minus 5 mmol/mol, p < 0.001) and the II (minus 4 mmol/mol, p = 0.004) groups. In the IC group, the HbA1c levels at follow-up were unchanged, while in the EC group it had increased by 2 mmol/mol (p = 0.213); however, this change was not significant. An ANCOVA, performed in order to adjust for baseline differences in HbA1c, showed a significant difference between the intervention groups (GI, II) and the external control group (EC), (p = 0.001). The treatment was changed for some of the participants between baseline and follow-up in all groups, however this did not influence the results.
Table 4. Baseline socio-demographics

<table>
<thead>
<tr>
<th></th>
<th>Total n=182 Mean (SD)</th>
<th>GI n=63 Mean (SD)</th>
<th>II n=34 Mean (SD)</th>
<th>IC n=34 Mean (SD)</th>
<th>EC n=51 Mean (SD)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>64.5 (9.58)</td>
<td>64.0 (8.72)</td>
<td>64.9 (11.10)</td>
<td>62.6 (10.61)</td>
<td>66.2 (8.75)</td>
<td>0.3681</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>68 (37.4)</td>
<td>20 (31.7)</td>
<td>13 (38.2)</td>
<td>16 (47.1)</td>
<td>19 (37.3)</td>
<td>0.5272</td>
</tr>
<tr>
<td>Men</td>
<td>114 (62.6)</td>
<td>43 (68.3)</td>
<td>21 (61.8)</td>
<td>18 (52.9)</td>
<td>32 (62.7)</td>
<td></td>
</tr>
<tr>
<td>Treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.0373</td>
</tr>
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<td>Diet</td>
<td>50 (27.5)</td>
<td>19 (30.2)</td>
<td>13 (38.2)</td>
<td>7 (20.6)</td>
<td>11 (21.6)</td>
<td></td>
</tr>
<tr>
<td>Oral</td>
<td>118 (64.8)</td>
<td>43 (68.3)</td>
<td>20 (58.8)</td>
<td>24 (70.6)</td>
<td>31 (60.8)</td>
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</tr>
<tr>
<td>Insulin/insulin and oral</td>
<td>14 (7.7)</td>
<td>1 (1.5)</td>
<td>1 (3.0)</td>
<td>3 (8.8)</td>
<td>9 (17.6)</td>
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</tr>
<tr>
<td>Smoking*</td>
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<td></td>
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<td>0.3173</td>
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<tr>
<td>Never smoked</td>
<td>78 (46.2)</td>
<td>31 (51.7)</td>
<td>12 (35.3)</td>
<td>16 (20.3)</td>
<td>19 (24.1)</td>
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<tr>
<td>Former smoker</td>
<td>77 (45.6)</td>
<td>23 (38.3)</td>
<td>17 (50.0)</td>
<td>12 (41.4)</td>
<td>25 (54.3)</td>
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<tr>
<td>Smokers</td>
<td>14 (8.3)</td>
<td>6 (10.0)</td>
<td>5 (14.7)</td>
<td>1 (3.4)</td>
<td>2 (4.3)</td>
<td></td>
</tr>
</tbody>
</table>

GI = Group intervention, II = Individual intervention, IC = Internal control, EC = External control.

*Valid percent p-values calculated with ANCOVA, Chi-square test for independence, Fisher's exact test.
<table>
<thead>
<tr>
<th>Table 5. Baseline clinical characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
<tr>
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<tr>
<td>Mean (SD)</td>
</tr>
<tr>
<td>HbA1C (mmol/mol)</td>
</tr>
<tr>
<td>50 (9.13)</td>
</tr>
<tr>
<td>HbA1C (%)</td>
</tr>
<tr>
<td>5.78 (0.88)</td>
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<tr>
<td>Body mass index (BMI)</td>
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<tr>
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<tr>
<td>Waist circumference (cm)</td>
</tr>
<tr>
<td>105.3 (13.72)</td>
</tr>
<tr>
<td>Total cholesterol (mmol/L)</td>
</tr>
<tr>
<td>4.94 (1.09)</td>
</tr>
<tr>
<td>HDL (mmol/L)</td>
</tr>
<tr>
<td>1.26 (0.36)</td>
</tr>
<tr>
<td>LDL (mmol/L)</td>
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<tr>
<td>2.85 (0.98)</td>
</tr>
<tr>
<td>Triglycerides (mmol/L)</td>
</tr>
<tr>
<td>1.92 (1.14)</td>
</tr>
<tr>
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<tr>
<td>137.3 (16.25)</td>
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<tr>
<td>Diastolic (mmHg)</td>
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<tr>
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<tr>
<td><strong>GI</strong></td>
</tr>
<tr>
<td>n=63</td>
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<tr>
<td>Mean (SD)</td>
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<tr>
<td>HbA1C (mmol/mol)</td>
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<tr>
<td>52 (9.63)</td>
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<tr>
<td>HbA1C (%)</td>
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<td>Waist circumference (cm)</td>
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<td>Total cholesterol (mmol/L)</td>
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<td>4.63 (0.88)</td>
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<td>HDL (mmol/L)</td>
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</tr>
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<td>LDL (mmol/L)</td>
</tr>
<tr>
<td>2.66 (0.82)</td>
</tr>
<tr>
<td>Triglycerides (mmol/L)</td>
</tr>
<tr>
<td>1.83 (1.29)</td>
</tr>
<tr>
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</tr>
<tr>
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</tr>
<tr>
<td>138.1 (18.21)</td>
</tr>
<tr>
<td>Diastolic (mmHg)</td>
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<td>81.5 (9.92)</td>
</tr>
<tr>
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</tr>
<tr>
<td>n=34</td>
</tr>
<tr>
<td>Mean (SD)</td>
</tr>
<tr>
<td>HbA1C (mmol/mol)</td>
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<tr>
<td>50 (8.98)</td>
</tr>
<tr>
<td>HbA1C (%)</td>
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<tr>
<td>5.8 (0.87)</td>
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<tr>
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<tr>
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</tr>
<tr>
<td>Waist circumference (cm)</td>
</tr>
<tr>
<td>107.0 (14.23)</td>
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<tr>
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<tr>
<td>5.02 (1.05)</td>
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<tr>
<td>HDL (mmol/L)</td>
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<tr>
<td>1.24 (0.24)</td>
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<tr>
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<tr>
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<tr>
<td>HbA1C (%)</td>
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<tr>
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<tr>
<td>Diastolic (mmHg)</td>
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<tr>
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<tr>
<td>HbA1C (%)</td>
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<tr>
<td>Triglycerides (mmol/L)</td>
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<tr>
<td>1.82 (0.82)</td>
</tr>
<tr>
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</tr>
<tr>
<td>Diastolic (mmHg)</td>
</tr>
<tr>
<td>82.8 (8.79)</td>
</tr>
</tbody>
</table>

*GI = Group intervention, II = Individual intervention, IC = Internal control, EC = External control.

*P-values calculated with one-way ANOVA with Bonferroni post hoc test.
The findings of this thesis show that diabetes nurses find it difficult to achieve patient-centred diabetes care and still focus on the traditional way of counselling, that is giving patients advice and expecting adherence. In traditional counselling the question of how to influence changed routines and habits in practice is more important than the question of how to sup-

Figure 3. HbA1c changes in various groups—adjusted for baseline differences.
port integration of illness and self-management in T2D (Study I). Patients, on the other hand, need to integrate illness existentially and emotionally at the same time as the practical aspects, that is, self-management (Study II), and thus need support for all these aspects. Supporting illness integration, including the emotional and existential aspects of illness, could be as effective as supporting changed routines for self-management. This thesis emphasizes that it is possible to follow the illness integration process (Study II) and that it is possible to identify triggers for turning points and therefore it is useful to discuss these issues with patients in self-management support (Study III). An evaluation of an RCT study revealed that illness integration is supported by patient-centred sessions conducted in groups or individually, and can improve HbA1c among patients with T2D (Study IV). In the following discussion, I have chosen to relate the findings to Leventhal’s et al. (1997) common-sense model, (see page 29-30), since the interventions relied on patients’ personal understandings of illness.

Illness experiences and patient-centred care

HCPs and patients have different beliefs and attitudes about self-management and treatment of T2D (Clark et al. 2003; Hörnsten 2004). Patients, with their experiences of living with a chronic illness, have a lot to add to the professional perspective on disease and treatment. Personal illness experiences are important to use in planning and performance of patient-centred care (Ekman et al. 2011). A patient-centred approach enables patients to reflect and discuss their own ideas about the illness, and HCPs to provide information and support about issues that patients request and find meaningful (Hörnsten et al. 2011a).

Diabetes nurses in study I described having a comprehensive view of patients and striving for patient-centredness in diabetes care. However, they also reported that blood sugar values and treatment goals were more important, and that they considered that many patients needed governance because they rejected self-management recommendations. Effects of gover-
nance on patients have been described by Hörnsten et al. (2011a). Patients with T2D experienced that diabetes nurses had a lesson to learn in self-management support. “Not making a mountain out of a molehill”; “the more routine”; the less life”; and “to err is human”, were themes that were identified and reflected a criticism of somewhat traditional aspects of diabetes care, that is a one-sided disease perspective, high adherence expectations, and a paternalistic attitude. Clark et al. (2003) reported that nurses, as opposed to T2D patients and physicians, believed that patients need special training in order to self-manage T2D. The nurses also viewed T2D as more severe than did the patients and the physicians. Nurses and physicians valued tight blood glucose control as more important than patients did. It is therefore important to consider that self-management is highly dependent on not only the patients’ knowledge and knowledge gaps, but also their personal goals and motivation for change as well as their life circumstances (Clark 2005). Patient-centred care relies on common ground for discussion and reflection about self-management and treatment between HCPs and patients.

The intervention in study IV was built on patient-centredness and resulted in improved HbA1c. One explanation for this improvement could be that the intervention emphasised the exchange of experiences of illness and self-management issues, something that other researchers have also highlighted as important (Tshiananga 2012; Deakin et al. 2005). The improvements in glycaemic control in study IV were interpreted as evidence that the patient-centred method worked. Discussing issues deriving from patients’ agendas is seen as an important aspect of patient-centred care. Using a patient-centred approach in diabetes care is seen as empowering, which is beneficial not only from a patient perspective but also from a disease management perspective (Funnell et al. 2004; White 2012). However, Lorig (2012) stated that interventions that are labelled as patient-centred are seldom patient-centred per se. In a literature review, she found that only three published articles out of 52 with a focus on chronic conditions were interpreted as patient-centred, as the interventions had not used patients’ per-
ceptions of what they regarded as as problems when the interventions were designed.

Compared to a previous intervention study by Hörnsten et al. (2005b), the improvement in HbA1c from our intervention (study IV) was smaller. Both interventions were built upon interviews with patients living with T2D (Hornsten et al. 2004) and used as a framework in study IV. The difference in HbA1c between group intervention and traditional care in Hörnsten’s et al. study was 10 mmol/mol, while a comparable difference (GI minus EC) in this study (IV) was 7 mmol/mol. However, there were some contextual differences between the two studies. In the study by Hörnsten et al. (2005b), the main researcher led all 10 sessions. Furthermore, the participants could choose to attend sessions in the daytime or the evening. In the current study (study IV) the number of sessions was reduced to six and they were implemented in the course of ordinary care in the daytime only and led by the local diabetes nurses at each HCC.

This intervention (study IV) consisted of both group intervention and individual intervention, and a similar improvement in glycaemic control was found in both groups which is promising since group interventions do not suit all patients with T2D (Ockleford et al. 2008). Group interventions, though, are recommended and reported as more effective in literature (ADA 2012; Deakin et al. 2005; IDF 2012; SBU 2009). In group education participants are supposed to support and inspire each other to implement lifestyle changes. Patients commonly share perspectives on being ill, and in group sessions they are in the majority and thereby become powerful. They can share also experiences and solutions that work and thereby minimise a top-down perspective in health promotion (Deakin et al. 2005; Jarvis et al. 2010).

**Illness integration and turning points in self-management**

Illness integration includes perceiving, understanding, reacting to and negotiating about illness and self-management decisions and actions. Below, a
model (Figure 3) of illness integration and self-management is suggested, which can be used to reflect upon in discussions between patients and HCPs. Illness integration can be seen as zipping life and disease together, that is, self-management support. The model implies a backward and forward movement, whereby people may struggle before deciding to act in congruence with their negotiation about, on the one hand, “life versus disease”, and on the other hand, “life with disease”. One assumption is that it is possible for HCPs to support people in finding solutions to the obstacles they experience and thereby facilitate the illness integration process among patients. Traditional diabetes care, described as real conditions in study I, seems to focus on advice about new routines and changed lifestyle, not on patients’ perceptions, or the emotional and existential experiences of having T2D.

According to the model of illness integration (Figure 4), illustrated by a zipper that aims to zip life and illness together to reach a health–illness–health transition, a health–illness transition concerns a passage and a process from a fairly stable state to another state triggered by change in health status, role relations, expectations or abilities. It requires incorporation of new knowledge and an altered behaviour, and changing the definition of oneself in the social context as healthy or not (Meleis 1991). The health–illness transition, which in this thesis is referred to as “becoming ill”, has been described as a process to achieving balance in living a personally meaningful life and at the same time experiencing the impact of the disease and its treatment (Kralik et al. 2004).
Figure 4. A model of illness integration in type 2 diabetes.
In this model, a new concept is suggested—that is “becoming successfully ill”. It can be defined as a health–illness–health transition, where the final health is seen as having an illness, but nevertheless seeing oneself as healthy, and where self-management is seen as a normal way of living, incorporated into daily life. When going through a health–illness–health transition as described in the model, the impact of the disease, self-management and treatment becomes minimised or non-existent.

The model (Figure 4) starts at the bottom of the zipper with patients’ perceptions of illness. These perceptions are crucial to discuss to support illness integration, because they incorporate information from the body, the social context, the media, the HCP’s and so on, creating common-sense or lay perspectives on illness (cf. Leventhal et al. 1984). According to the common-sense model, this could imply perceiving symptoms and understanding and explaining the severity and health risks of T2D. However, it is important to consider that patients’ perceptions of illness are not always in accordance with HCPs’ perceptions or medical facts (cf. Leventhal et al. 2003; Mann et al. 2009). These illness perceptions will guide how patients act upon their illness and perceptions about severity and have been reported to be associated with better diabetes outcomes, active problem-solving and increased motivation for self-management (Harvey et al. 2009). Perceptions of severity and related risks seem to trigger self-management actions effectively (Studies II–III; cf. Leventhal et al. 2003). If symptoms are lacking and T2D is seen as a non-severe illness or a normal state that comes with age it is probable that motivation for self-management activities is low and not seen as meaningful (Thoolen et al. 2008). Some patients with low perceptions of severity are, though, compliant with HCPs’ advice and follow it for a while, however, seldom over the longer term. If, on the other hand the symptoms and T2D are seen as too severe, chaos or panic may occur (Study II), and self-management may be inadequate or experienced as too burdensome (cf. Leventhal et al. 2003).
After perception, the process continues with an emotional reaction to the diagnosis. This reaction is closely related to the perception of severity and the health threat from the disease. Some kind of emotional reaction seems to be important in illness integration (Sandén-Eriksson 2000; Thoolen et al. 2008). If T2D is not seen as any threat, will appropriate self-management probably not be motivated or performed. Fear, particularly fear of complications, can have a motivational effect in T2D (cf. Leventhal et al. 2003). It is, however, important to consider that not all patients experience fear or consider T2D as a severe illness (Clark et al. 2003). Almost 50% of all patients across the European countries have been reported as not considering T2D as a severe illness, and nearly three-quarters have been reported as believing that they have good metabolic control, despite the fact that their HbA1c levels are not under control (Choose control survey data, 2006; Mann et al. 2009). This indicates that for many individuals it may be sufficient to reflect upon the severity of T2D and fear of complications together with their HCPs. It is important to consider that a moderate emotional response (Study II) is considered as most efficient since too low or too high a response could lead to a passive attitude or panic, neither of which improves self-management (Harvey et al. 2009).

After perception and reaction, the process continues with negotiation, that is, negotiation about “life versus disease” or “life with disease”, where the later state is preferable. Studies II and III reported that it is essential to negotiate and take stands about self-management that is, to select strategies that enable a changed behaviour but also concern removal of obstacles for it. In CSM, this process refers to the term problem-solving. In order to reduce the health threat due to the disease, the patients, according to CSM try to incorporate disease information and the reactions to the danger. This can lead to taking a stand about improved self-management (cf. Leventhal et al. 2003). When it comes to a chronic illness such as T2D and its self-management, the patient is the active problem-solver and therefore has to negotiate and figure out the personal meaning of the illness and illness perception and how to manage the illness live well despite the illness, which
can be seen as balancing act (Studies II-III). Negotiation about living with an illness such as T2D means constantly making decisions about self-management, which are highly dependent on other life circumstances. These decisions are also related to an uncertainty, since one never know if whether it will be possible to manage them, due to disease progression and uncertainty about when or even if complications will occur (cf. Clark 2005). In a meta-ethnography including analysis of 43 qualitative studies and aiming to advance the understanding of the lived experience of diabetes, Paterson et al. (1998) stated that it concerned a decision and a balancing act to assume control. The balancing act included to negotiating between sometimes contradictory aspects of being ill, that is, being controlled or controlling the disease, wanting to be in control and needing others, accepting oneself as a person with diabetes and maintaining a positive self-concept, developing patterns in self-management and adapting to changes, learning the basics of the disease and management and understanding the disease in a personally meaningful way, seeking help and being unwilling to ask for help, learning to manage diabetes and feeling not diseased and lastly, expressing needs to HCPs and not being seen as a troublesome patient. This negotiation about changed lifestyle can be viewed as negotiating about cost-benefits for today and the future. For example, improved physical activity and changed diet can be associated with many costs and few benefits in the short term, such as inconvenience, loss of pleasure and discomfort. Over the longer term, these lifestyle changes may have many benefits and thereby small costs, for example, longer lifespan improved functional status and decreased risk for complications (Hall et al. 2007).

After perception, reaction and negotiation, the process continues, and sometimes patients reach a so-called turning point when they experience that they must take a decision and act upon it. They cannot turn back, since they are in a life and death struggle. Furthermore, they are at a crossroads, and at this moment they experience being the one who decides and who can change the outcome (Study III). The negotiation is influenced by personal expectations and goals (Study II). If the goals for self-management
activities are seen as self-chosen, meaningful and achievable, and if the patients perceive that they have enough confidence and capability, that is “self-efficacy”, to reach the goals, the probability that they will perform these self-management activities is higher. To the contrary, if a goal seems to be unattainable, lifestyle changes seldom will happen (Scheier et al. 2003). It is therefore important for an HCP to highlight patients’ self-efficacy beliefs about self-management simultaneously with reflecting upon their personal contexts to identify realistic, attainable goals, reducing obstacles and increasing opportunities for change (cf. Donovan et al. 2007).

After perception, reaction, negotiation and reaching a turning point in self-management, the illness integration process continues with an evaluation of performed self-management activities (Study II). If self-management succeeds, resulting in, for example, improved glycaemic control, reduced weight and so on, or improved well-being, these actions are evaluated as successful and may increase the self-efficacy and motivation to continue with the activities that eventually becomes habits (Study II) (cf. Leventhal et al. 2003). This has been described by Paterson (2001) as the paradox whereby well-being, not the disease is in the foreground of life, but disease management becomes a prerequisite to stay well. When diabetes self-management is integrated into people’s lives, they are in balance for a shorter or longer period. However, if complications occur, or if increased effort for self-management is needed due to disease progression, this balance may be lost and a new struggle begins (Study II; Kneck 2011; Paterson 2001).

In summary, it is complex and takes time to integrate an illness such as type 2 diabetes. Getting a clinical diagnosis is seldom related to immediate integration of illness and self-management. With this knowledge, HCPs have a responsibility to adapt patient education and support in T2D after patients’ needs and preferences. With a patient-centred approach, HCPs should interview patients about their perceptions about and experiences of illness (Ekman et al. 2011) to support illness integration and self-management (Huang et al. 2005). This knowledge may bridge the gaps between
medicine and life world experiences and also increase patient satisfaction with care (Hornsten et al. 2005a). Traditionally, HCPs have focused on informing and helping patients to create routines to improve self-management and thereby glycaemic control. This has not always been successful, particularly not over longer periods. Karlsen et al. (2011) reported that HCPs support do not always improve glycaemic control or reduce the distress due to T2D, which must be taken into consideration. It is therefore important to practise and provide training in patient-centred methods that enhance the HCPs’ self-efficacy to use patient-centred methods and to influence the patients’ perceptions of their ability to manage their illness, that is, patients’ self-efficacy.

There is no method for self-management support that fits and satisfies all patients. Brief and standardised self-management support approaches without patient-centred dialogues are not favoured by patients. HCPs need to understand each patient’s views on self-management and how they integrate it into their lives (Furler et al. 2008). Patient-centred methods, that include exploring patients’ experiences and perceptions, desires and needs as well as social and cultural circumstances increase the probability for improved patient satisfaction, patient empowerment and self-management (cf. Furler et al. 2008). Increased patient satisfaction and patient empowerment is reported to be related to accessibility when needed; trust in HCPs’ competence; a personal, confirming, welcoming and equal encounter; and collaborative goal setting (Hornsten et al. 2005a; Nygårdh et al. 2011). Thorough listening to patients is emphasised in patient-centred care. Skinner et al. (2008) stated that talking less and being less didactic as an HCP was related to improved metabolic control among patients. However, several studies have stated that it is difficult to change education style and that there is a need for continuous support of HCPs to change counselling style (Adolfsson et al. 2004; Adolfsson et al. 2009; Ponte et al. 2003).
Methodological considerations

To investigate different aims deriving from different scientific paradigms, both qualitative (Studies I–III) and quantitative methods (Study IV) have been used in this thesis. The qualitative data collection included individual interviews (Studies II–III) and focus group interviews (Study I).

Most important in qualitative research is to collect rich data. A welcoming and friendly approach where the interviewer creates a positive interaction facilitates getting rich data (Peek et al. 2009). Probing questions has further been used to get a deeper understanding of the investigated subjects (Kvale 1996). A strength of focus group interviews is that they offer the possibility of collecting experiences and reflections from a group of participants with similar interests. A disadvantage can be that group thinking may occur and participants who do not agree hesitate become involved in discussions. However, a moderator is useful for getting all participants involved and to maintain focus and inspire a broader or deeper discussion (Ekblad et al. 2002). The strength of collecting data through as individual interviews (Studies II–III) is that it is an appropriate method to approach people’s lived experiences, for example, to find out what it is like to live with and self-manage an illness such as T2D (Sandelowski 2000).

I have interviewed all participants and transcribed all the interviews in study I and study III while the main supervisor interviewed the participants in study II. It may be a benefit to perform the interviews and transcriptions by oneself as being mainly responsible for the analysis. A reason for this is that the analytic process starts during the interviews and is influenced by the researcher’s pre-understanding (Mishler 1986). The text is created and develops in interaction between the participants and the interviewer which should not be seen as a weakness (Kvale 1996; Schreier 2012). In the analyses, I have tried to continuously reflect and be aware of my own pre-understanding in the creative process. I have tried to explain how the find-
ings have been developed, by providing and using by quotes by way of example.

Trustworthiness in qualitative research could be gained, for instance, through discussions in the research group about analysis and labelling of codes, categories and themes in order to avoid over-interpretations (Graneheim et al. 2004; Schreier 2012). The research team’s diverse experiences of diabetes care have been seen as a benefit and have led to fruitful discussions about the interpretation of data. The preliminary findings on an abstracted level have continuously been compared with the original text and often have been reformulated after discussions in the research team (cf. Graneheim et al. 2004; Schreier 2012).

Qualitative research is contextual but some of the results may be transferable to other contexts (Graneheim et al. 2004). The main findings regarding illness integration and self-management may be applicable to other contexts in chronic illnesses other than T2D.

The choice of qualitative content analysis was seen as satisfying to describe variations of phenomena (Studies I–III). In study II, GT could have been used as well as qualitative content analysis since the result is reported as a process and GT beneficially is used in such analyses. Furthermore, study II was a secondary analysis of interviews performed by the main supervisor and thereby a theoretical sampling was troublesome. Corbin and Strauss (2008), however, state that it is possible to use interviews that already have been performed in a GT approach. Since the questions formulated were process-oriented and in a timeline, I have later found that qualitative content analysis was an appropriate method for the aim of study II.

The limitations in the intervention study (Study IV) concerned the participation. Only nine of the 19 HCC managers agreed to participate in the study. It is not known if the non-participating HCCs differed from the participating ones. However, they were located both in rural areas and centrally around all three cities in the County Council of Västerbotten, which is considered a strength.
Another limitation in study IV was that a limited number of patients were diagnosed with T2D at some of the HCCs, and therefore the recruitment of participants included all those diagnosed and was close to the minimal limit according to the power calculation. The inclusion criterion was initially being diagnosed with T2D within two years, but an increase to within three years was necessary to achieve sufficient power. Among those excluded were nine patients who were diagnosed with T2D in the medical record, but who, when they got the invitation to participate in the study, said that they did not have T2D or had been diagnosed with type 1 diabetes. These persons were excluded from the study. Furthermore, it has later been detected that in Västerbotten County Council a large proportion of patients in the computer data system have been diagnosed with unspecified diabetes, which could be a bias in sampling (Rolandsson et al. 2012).

Previously, no clear gender difference have been reported in the prevalence of T2D in Sweden (Wändell et al. 2004). However, the result from NDR 2012 reported that a majority (56.2%) was men (NDR, 2012). In study IV more men than women were diagnosed with T2D in the computerised diagnosis register, which is reflected in the final sample. The group that declined participation (n = 132) in study IV constituted 40%, which is quite a high proportion. Out of ethical considerations, we did not asked the reasons for non-participation in study IV, but many of the participants explained why they did not want to participate. These reasons were categorised as limited time (31.1%), not interested (9.8%) and not aware of having diabetes (8.3%). The remaining (32.6%) did not give any reason for electing not to participate. Reasons for drop out (n = 13) during the intervention were did not given any reason (54%), time constraints (23%), moving from the area (8%) and difficulties to reaching the HCC (8%).
Conclusion and clinical implications

Diabetes care has been reported to be non-optimal since too few patients reach recommended treatment goals, and patients express dissatisfaction with diabetes care. This thesis however, supports previous studies that advocate for patient-centred care which seem to support integration of illness and self-management. Patient-centred care implies that patients are involved and have opportunities to express their needs and perceptions about illness, self-management and treatment. Focusing on and reflecting on emotional and existential issues related to having and managing an illness seems to facilitate illness integration and self-management. Patients’ experiences of illness are central to their inner motives for change, and self-management support preferably emanates from a patient perspective. Enhancing self-management towards turning points seems to be crucial and triggers for such turning points can be identified and highlighted in counselling. It is thereby possible to speed up the integration of illness and self-management. Research about how to implement patient-centred care is requested and needed to identify which methods in counselling that improve knowledge, interaction and support that fit with the patients’ needs. The result in this thesis can be a good example of the possibility of implementing patient-centred diabetes care in practice.

This thesis points to a need for nurses to focus more on patient perspectives and patient-centredness where illness integration should be facilitated, not only in terms of self-management practice. Nurses thereby can influence and assist people with T2D to integrate illness and simultaneously its management. It is possible to train diabetes nurses to use a more patient-centred approach in primary health care. Nurse-led, patient-centred self-management support improves metabolic control and is thereby recommended. Individual support works as well as group support. Patient-centred care seems to facilitate both illness integration and self-management in T2D and is probably a useful method in other lifestyle-related chronic illnesses where self-management is important.
Future research

Diabetes is common and particularly among people with psychiatric co-morbidities and these people are often at higher risks for complications. Unfortunately, they are often excluded in research studies. The next step in my own research would be to interview people with psychiatric comorbidities, adapt, and use the model of illness integration in new intervention studies to support self-management in this context. Other patient groups besides those with T2D would also be interesting to intervene among, for example, those with hypertension, obesity and other lifestyle-related conditions. An increased focus on pre-diabetes, those with previous gestational diabetes and other people living with risk for diabetes would also be beneficial from a health economic perspective.
Summary in Swedish


En viktig uppgift för diabetessköterskan är att stödja patienter att hantera sin sjukdom i det dagliga livet. Grupputbildning och patientcentrerad vård är arbetssätt som rekommenderas eftersom dessa beskrivs medföra förbättrad sjukdomshantering och underlättad sjukdomsintegration vid typ 2 diabetes, bland annat genom en ökad tilltro att själv klara av att hantera sjukdomens krav. Trots ökande evidens för att patientcentrerade arbetssätt är att föredra så tvekar sjukvårdspersonal ibland att använda sig av dessa och anger skäl som tidsbrist samt avsaknad av kunskap och verktyg som hinder. Alltför få patienter når målnivåerna för blodsocker vilket medför ökad risk för komplikationer, ökat lidande och ökade samhällskostnader. Det behövs fler randomiserade studier som fokuserar på patientcentrerad
vård inom diabetesområdet och som utvärderar effekter på egenvårdshan-
tering och blod-sockerbalans för att förstå hur man bäst stödjer människor
att hantera sjukdomen. Avhandlingen innehåller tre kvalitativa studier som
beskriver diabetesköterskors syn på diabetesvården samt patienters erfarenheter
av sjukdomshantering och sjukdomsintegration. Ytterligare ingår en kvantitativ
studie som utvärderar en patientcentrerad intervention bestående av egenvårdsstöd
individuellt eller i grupp.

Avhandlingens övergripande syfte är att beskriva integration av
sjukdom, sjukdomshantering och patientcentrerad support vid typ 2
diabetes.

Studie 1 visade att diabetesköterskor upplevde det svårt att uppnå
den ideala diabetesvården. De fokuserar oftast på att ge patienter råd och
förväntar sig också att patienterna följer dessa råd och en patientcentrerad
vård var därmed svår att uppnå i praktiken. Studie 2 visade att patienterna, å
andra sidan, behöver reflektera kring de känslomässiga och existentiella
aspekterna av att leva med en kronisk sjukdom som typ 2 diabetes för att
mer effektivt integrera sjukdomen och dess hantering i livet. Det är av vikt
att förstå hur patienten upplever och reagerar på sjukdomen samt väljer att
förändra sina levnadsvanor samt också hur patienten utvärderar dessa
förändringar. Studie 3 beskriver vad som kan utlösa en plötslig förändring
eller så kallad ”turning point” i sjukdomshanteringen. Uttalanden liknande
”Nu är det på liv eller död; Jag står vid ett vägskäl och det finns ingen
återvändo; Det är upp till mig själv, eller; Det är möjligt för mig att klara av
det, tyder på att en ”turning point” är nära förestående. Sådana uttalanden
är möjliga att identifiera och viktiga att diskutera och reflektera kring för att
effektivt stödja patienten att hantera egenvården.

Studie 4 innefattar en utvärdering av en patientcentrerad intervention.
Interventionen byggde på sex teman, genererade från patientintervjuer om
personliga förståelsemodeller vid typ 2 diabetes och som diskuterades under
supportträffar. Dessa teman var följande: Bilden av sjukdomen, Innebörden
i att få en diagnos, Integrationen av sjukdomen i livet, Utrymmet för egen-
vården, Ansvaret för egenvården samt Framtiden med sjukdomen. Tradit-

tionell diabeteskunskap och fakta förmedlades endast om patienterna efter-
frågade detta eller om oklarheter i förståelse av diabetesjukdomen fram-
kom. Totalt deltog 182 patienter i interventionen fördelade på grupp-inter-
vention (n = 63) (kvinnor 32%, män 68%), individuell intervention (n = 34) 
(kvinnor 38%, män 62%) intern kontrollgrupp (n = 34) (kvinnor 47%, män 
53%) och extern kontrollgrupp (n = 51) (kvinnor 37%, män 63%). Resul-
tatet visade att såväl gruppintervention som individuell intervention signifi-
kant kan förbättra det genomsnittliga långtidsvärdet för blodsocker 
(HbA1c) bland patienter med typ 2 diabetes.

Denna avhandling pekar på att det finns ett behov av att 
diabetessköterskor i högre grad fokuserar på patienters perspektiv på 
sjukdom och egenvård. Ett sådant, mer patientcentrerat arbetssätt, är 
effektivt för att stödja sjukdomsintegration och sjukdomshantering. Att 
fokusera på patientens sjukdomsupplevelser inklusive känslomässiga och 
existentiella aspekter av att leva med och hantera en sjukdom som diabetes 
kan innebära förbättrade sjukdomshantering och metabol balans även på 
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References


Renders CM., Valk GD., Griffin SJ., Wagner E., van Eiik JT. & Assendelft WJJ. (2001). Interventions to improve the management of diabetes...
mellitus in primary care, outpatient and community settings.  
*Cochrane Database of Systematic Reviews*, 4, doi:10.1002/14651858.


UK Prospective Diabetes Study Group (1999). Quality of life in type 2 diabetic patients is affected by complications but not by intensive policies to improve blood glucose or blood pressure control (UKPDS-37). *Diabetes Care*, 22, 7, 1125-1136.


