

# **Proximity and distance**

## **Challenges in person-centred care for diabetes specialist nurses in primary healthcare**

**Eva Boström**



**Department of Nursing**  
Umeå University, 2013

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**for diabetes specialist nurses**  
**in primary healthcare**

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*Walking down to the sea, with the hills behind me, with the miles inside me,  
what lies before me is immense, a glittering and shining expanse, both limit  
and release*

*On Looking at the Sea by Thomas A Clark*



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# Abstract

**Background** Type 2 diabetes demands self-management over time, to maintain health and reduce the risk for diabetes complications. However, despite efforts, many persons with type 2 diabetes are not reaching the treatment targets. In diabetes, person-centred care and group education are recommended. Diabetes specialist nurses (DSNs) working in primary healthcare have an important role in supporting patients with type 2 diabetes in their self-management to adapt to the demands of the disease in everyday life. Therefore, it is important to explore the DSNs' professional role and their experiences of practising person-centred care. The overall aim of the thesis was to explore the professional role of DSNs in primary healthcare, and to describe their experiences of person-centred diabetes care.

**Methods** The thesis includes three studies with qualitative, and one with a quantitative, approach. Data collection consisted of focus group interviews, individual interviews, observations, and questionnaires. Qualitative content analysis and statistics were used in the analysis. In studies I and II, 29 and 31 DSNs participated, respectively. In study III, 10 DSNs and 44 persons with type 2 diabetes participated. Lastly, in study IV, 10 DSNs participated.

**Results** The results in the thesis showed that DSNs have a complex and multifaceted professional role that entails striving to be an expert, a fosterer, a leader, an executive, and a role model, which they found challenging. The DSNs perceived high job demands, such as decision-making and learning. The thesis also showed that the interaction between DSNs and persons with type 2 diabetes shifted from empowerment to authority struggles during group support sessions based on person-centred care. The experience of person-centred care was described as enriching, but DSNs also expressed ambivalence, related to an altered professional role.

**Conclusion** There is a desire by DSNs to be close to persons with type 2 diabetes, although they have several challenges to fulfil, which makes it difficult to uphold a relation with proximity; thus, distance is also present. Even though person-centred care is recommended in healthcare, and despite DSNs' efforts to practise PCC, the result of this thesis shows that it also implies an altered professional role for DSNs that has to be addressed.

**Keywords** Diabetes specialist nurses, professional role, self-management support, type 2 diabetes, caring relation, power relations, person-centred care

# Sammanfattning på svenska

Typ 2 diabetes kräver sjukdomshantering över tid för personer för att behålla hälsa och minska risken för diabeteskomplikationer, men trots ansträngningar uppnår många patienter inte behandlingsmålen. I vården av personer med typ 2 diabetes rekommenderas ökad person-centrering samt grupputbildning. Diabetessjuksköterskor i primärvården har en viktig roll att stödja personer med typ 2 diabetes att anpassa sjukdomens krav till vardagslivet och därför är det av betydelse att utforska deras yrkesroll och deras erfarenheter av att praktisera person-centrerad vård. Avhandlingens övergripande syfte var att utforska diabetessjuksköterskors professionella roll i primärvården och beskriva deras erfarenheter av personcentrerad diabetesvård.

Avhandlingen innehåller tre studier med kvalitativ och en med kvantitativ ansats. Datainsamlingen bestod av fokusgruppsintervjuer, individuella intervjuer, observationer samt enkäter. Kvalitativ innehållsanalys och statistiska metoder användes i analysen. I delstudie I och II deltog 29 respektive 31 diabetessjuksköterskor. I delstudie III deltog 10 diabetessjuksköterskor och 44 personer med typ 2 diabetes. Slutligen, i delstudie IV deltog 10 diabetesjuksköterskor.

Avhandlingens resultat visar att diabetessjuksköterskor har en komplex och mångfacetterad yrkesroll, som innebär en strävan efter att vara expert, fostrare, ledare, utförare och förebild, vilket också är kravfyllt. Diabetessjuksköterskorna upplevde generellt höga arbetskrav såsom krav på eget beslutsfattande och att vara uppdaterad med ny kunskap. Resultatet visade även att deltagandet i en personcentrerad intervention innebar en relation som innehöll både närhet och distans. Erfarenheten upplevdes berikande men ambivalens uttrycktes, relaterat till en förändrad yrkesroll.

Diabetessjuksköterskor strävar efter en nära relation med personer med typ 2 diabetes, men de har samtidigt många andra utmaningar att hantera, vilket försvårar för dem att upprätthålla en nära relation, och distans är därmed också närvarande. Trots rekommendationer om ökad personcentrering i vården samt diabetessjuksköterskors ansträngningar att praktisera personcentrerad vård visar denna avhandling att detta också innebär en förändrad yrkesroll för diabetessjuksköterskor som måste bemötas.

# Abbreviations

DIVA 2	Diabetes Intervention in Västerbotten, part 2
DSN	Diabetes specialist nurse
GP	General practitioner in primary healthcare
HCP	Healthcare professionals (nurses and GPs)
HbA1c	Haemoglobin A <sub>1c</sub> , or glycated haemoglobin test, which provides information about the average levels of blood glucose for the past 2–3 months
NDR	National Diabetes Register
PCC	Person-centred care
PHN	Primary healthcare nurse
PHC	Primary healthcare centre
T2D	Type 2 diabetes



## Original papers

This thesis is based on the following papers, which will be referred to by their Roman numerals in the text.

I: Boström E, Isaksson U, Lundman B, Sjölander AE & Hörnsten Å (2012): Diabetes specialist nurses' perceptions of their multifaceted role. *European Diabetes Nursing* 9, 39–44.

II: Boström E, Hörnsten Å, Lundman B, Stenlund H & Isaksson U (2013): Role clarity and role conflict among Swedish diabetes specialist nurses. *Primary Care Diabetes* 7, 207–212.

III: Boström E, Isaksson U, Lundman B, Graneheim, UH & Hörnsten Å: Interaction between diabetes specialist nurses and patients during group sessions about self-management in type 2 diabetes. *Submitted 2013*.

IV: Boström E, Isaksson U, Lundman B, Lehuluante A & Hörnsten Å: Patient-centred care in type 2 diabetes – An altered professional role for diabetes specialist nurses. *Submitted 2013*.



# Preface

During my years as a nurse at a thorax surgery ward and as a primary healthcare nurse within the municipality school healthcare, I have always had an interest in how we as nurses perceive our professional role and respond to and interact with people with different problems or diseases, while encouraging them to make lifestyle changes. As a teacher at Umeå University, I came in contact with a research project in the field of diabetes, and I had the opportunity to apply for a position as a doctoral student in the project Diabetes Intervention in Västerbotten, part 2 (DIVA 2). With this thesis, I will describe the challenging professional role of diabetes specialist nurses in primary diabetes care.

# Introduction

The focus of this thesis is to explore the professional role of diabetes specialist nurses (DSNs) in the diabetes field within primary healthcare, and their experiences of practising person-centred care. In this thesis, which is a part of the DIVA 2 project, I explore how DSNs perceive themselves and the psychosocial aspects surrounding their professional role, and further, I explore their interaction with persons with type 2 diabetes (T2D), and how they describe their experiences of practising person-centred care. In Sweden, there is a tradition of referring to nurses in diabetes care as diabetes nurses. The specialist nurse title is protected, and is used only by registered nurses in Sweden who have been granted the right to call themselves specialist nurses (National Board of Health and Welfare 2013). To become a specialist nurse in Sweden requires an education that consists of at least one year of university studies. There are several possibilities for further education within nursing, as, for example, to become a primary healthcare nurse, which a majority of diabetes nurses in primary diabetes care have done. Most of the nurses in diabetes care have an additional 15–30 credit in diabetes care, and in the description of competence, for education of specialist nurses in diabetes care, a master's degree in diabetes care is further recommended by the Swedish Association for Nurses in Diabetes Care, SFSD (2006). During 2013, the SFSD have applied to the Council of Legislation for a protected professional occupational title of specialist nurse within the field of diabetes. In this thesis I will anticipate a favourable decision, and henceforth refer to nurses involved in diabetes clinics in primary healthcare as DSNs.

Type 2 diabetes is the most common of all types of diabetes, and the main responsibility for T2D care falls to the primary healthcare centres (PHC) in

different municipalities (National Board of Health and Welfare 2010). Diabetes care in general is organised and planned according to international guidelines, such as those of the American Diabetes Association (ADA 2012) and the International Diabetes Federation (IDF 2012a), and in Sweden also according to national and regional guidelines (National Board of Health and Welfare 2010). T2D is a chronic disease that requires lifelong treatment and demands lifestyle changes to avoid or postpone complications such as hypertension, vascular diseases, nephropathy, retinopathy, and neuropathy. Approximately 10% of the care budget in Sweden is allotted to diabetes treatment (Swedish National Diabetes Register, NDR 2012), and the costs are expected to rise with an increasing number of people with T2D (ADA 2012). The national guidelines (National Board of Health and Welfare 2010) recommends that people with T2D take action regarding their self-management and their illness, since their self-management choices in daily life are determinant of their T2D in future. A large number of people with T2D do not reach treatment targets (Eliasson *et al.* 2005, Jansson *et al.* 2007, NDR 2012), and the system of diabetes care has a large responsibility in attending to patient appointments at the rate needed. Despite guidelines and quality registers, a large number of persons with T2D are overweight, and too few of them engage in physical activity (NDR 2012). In addition, it has been reported that misunderstandings about the disease and the treatment are common among those with T2D (Holmström & Rosenqvist 2005). The views of satisfactory care held by persons with T2D (Hörnsten *et al.* 2005) are not always consistent with nurses' perceptions of care (Hörnsten *et al.* 2008a). Both perspectives, the healthcare biomedical perspective and the life-world perspective of the person with T2D, are important, and DSNs need to respond to both, which can be difficult to balance (Adolfsson 2008, Holmström *et al.* 2003). Person-centred care (PCC) and empowerment are recommended in diabetes care; however, practising PCC has been found to be difficult for professionals (Holmström *et al.* 2003, Hörnsten *et al.* 2008a). For future optimal diabetes care, it is desirable that persons with T2D are involved in their care and share decision-making with professionals. An increased awareness among DSNs about their professional role, and knowledge about barriers and opportunities of practising person-centred care, may promote the support of persons with T2D in self-management and improve patients' outcomes.

# Background

## The diabetes specialist nurse

### *The professional role*

There are several definitions of a profession, and there is not one sole description. According to SSF, the Swedish Society of Nursing (SSF 2013), and the Swedish Association of Health Professionals (Vårdförbundet 2013), a profession requires a science-based education, legislation, and a professional organisation within their field, such as SFSD, the Swedish Association for Nurses in Diabetes Care, for the DSNs (SFSD 2006). In this thesis, I am referring to the DSNs' professional role. A role has been defined as the set of descriptions defining behaviour appropriate for a member occupying a particular position (Biddle 1979). In addition, the concept of a role centres upon behaviours that are characteristic of persons in a specific context. A role can be achieved either by individual efforts or by education (Llahana 2005). A role can also be ascribed by factors outside one's control, such as gender, age, class, or ethnic origin. The professional role of DSNs depends on the context, including environment and organisation; personal factors, such as characteristics, attributes, and motivation; and role performance, such as reciprocal interaction and expectations, both of oneself and of others (Llahana 2005).

### *The history of the profession*

In the early twentieth century, even before the discovery of insulin therapy, diabetes nursing had evolved in some countries (Allen 2003, MacKinnon 2012). Since then, nurses have educated persons with diabetes and their families about diet, exercise, and monitoring of urine glucose levels, and later on, blood glucose levels and administration of insulin. In the United States the first diabetes nursing course was offered in the 1920s (Allen 2003), while in the United Kingdom the first such course was conducted in the late 1970s (MacKinnon 2012). In Sweden, diabetes courses for nurses began to be provided in the 1970s, and simultaneously, diabetes clinics opened in hospitals. During the 1990s the responsibility for T2D care moved from the hospitals to the primary healthcare centres, which have the main responsibility for T2D care today (National Board of Health and Welfare 2010), with the care being commonly organised within the County Council organisations (Adolfsson *et al.* 2010).

### *The profession internationally*

A DSN has been described as a specialist nurse working with diabetes clinics in hospitals or community settings to deliver care, education, and support to persons with diabetes and their families (Funnell *et al.* 2006, Loveman *et al.* 2004, Peters *et al.* 2001). Worldwide, there are differences regarding how common DSNs are and what they are called, and concerning their autonomy (cf. van den Berg *et al.* 2008). According to FEND, the Foundation of European Nurses in Diabetes (FEND 2013), approximately half of the countries in Europe have DSNs. In the UK, there are clinical nurse specialists, advanced nurse practitioners, and nurse consultants, in addition to DSNs involved in nurse-led diabetes clinics (Avery & Butler 2008, James *et al.* 2009). The DSNs in the UK are described as having extended knowledge and skills in diabetes management, and their professional role has been described as that of an educator, counsellor, manager, communicator, and innovator, having responsibility for the care they provide (Llahana 2005). In addition, DSNs work in care teams to provide comprehensive diabetes service, and to educate and support patients and colleagues as well (James 2011).

In the US there has been a long tradition of nurses working in diabetes care. They are commonly referred to as either diabetes educators (Barlow *et al.* 2005) or certified diabetes educators (Funnell *et al.* 2006), similar to diabetes nurse educators in Australia (Tapp *et al.* 2004). Irrespective of the titles they are given, there are similarities worldwide among nurses working in diabetes care and Swedish DSNs, concerning their skills and work performance (Adolfsson *et al.* 2007, Andersson *et al.* 2009, National Board of Health and Welfare 2010, SBU 2009, Wikblad 2012, Wredling & Ahlin 2005).

### *The profession in Sweden*

In Sweden DSNs are registered nurses, in the last decades requiring a bachelor's or master's degree. Most of the DSNs in Swedish primary health care have a postgraduate education as a primary healthcare nurse (PHN), and have the right to prescribe special medical devices and medication, according to a special list from the National Board of Health and Welfare (2001). The DSNs in focus in this thesis are nurses working in diabetes clinics, having responsibility for a diabetes specialist clinic at a PHC, in collaboration with a general practitioner (GP) (National Board of Health and Welfare 2010). In a study about Swedish diabetes care in primary healthcare Adolfsson *et al.* (2010) demonstrated that most of the PHCs in Sweden have DSNs, who work part-time as a DSN for in median 18 hours/week. Most of them have an additional 15 ECTS (European Credit Transfer System) points

in postgraduate education in diabetes care. In a document describing the competence and proposed education for the registered nurse specialising in diabetes care (SFSD 2006), it is recommended that DSNs complete further continuing education in diabetes care (16–30 credits). In addition, a master's exam followed by a PhD is encouraged, but seldom undertaken. However, the DSNs' professional accreditation requires competencies and knowledge based on science and proven experience in nursing science, medical science, leadership, and pedagogy (SFSD 2006). The DSNs in primary healthcare often combine their duties with work as a primary healthcare nurse (PHN), carrying out home care, telephone consultations, and clinical care as well (Andersson *et al.* 2009). Preventive activities are vital in diabetes care, including support of patients' self-management, but it has been stated that it is difficult to prioritise patient education and self-management support (Adolfsson *et al.* 2010, Andersson *et al.* 2009), as care is often oriented to medical tasks at the PHCs (Wilhelmsson & Lindberg 2009).

### *Work tasks*

The purpose of the DSNs' work is to support persons with T2D to manage the disease with preserved wellbeing, and simultaneously to achieve treatment targets. The DSNs' professional role in diabetes care includes identifying and making assessments about patients' problems, needs, and personal capabilities, while taking resources, strategies, psychosocial context, lifestyle, and disease perspectives of persons with T2D into account (Wikblad 2012, Wredling & Ahlin 2005). Together with persons with T2D, DSNs identify problems and resources used for planning care and individualised treatment goals, and offer support, updated education, and dietary advice based on the latest recommendations (Wikblad 2012, Wredling & Ahlin 2005). Examples of medical work tasks are controlling metabolic measures, in collaboration with GPs adjusting per oral medicine and insulin doses, performing foot examinations and other physical examinations, recording documentation in patients' records (Wredling & Ahlin 2005, Andersson *et al.* 2009, Wikblad 2012), in NDR (2012), and referring patients and coordinating care between caregivers.

The DSNs also provide support for all the different problems connected to the disease and favour a relationship with the person with T2D, which may facilitate the persons' ability to take responsibility for self-management and solve diabetes-related problems that occur in their daily lives (Wikblad 2012, Wredling & Ahlin 2005). Since the DSNs are nurse specialists, they also have an obligation to stay current with the latest diabetes knowledge, to be experts, and to educate colleagues (MacKinnon 1998). However, in a Delphi study in the UK, the DSNs expressed reluctance to engage and edu-

cate colleagues; these activities were seen as functions to be undertaken by those in academia (Peters *et al.* 2001).

Both nurses and physicians agree that nurses should take a larger role in management of diabetes. From the DAWN study, it is reported that nurses in diabetes care provide better education, spend more time with patients, are better listeners, and know their patients better than do physicians (Siminerio *et al.* 2007). Several authors have proposed that DSNs should have increased responsibility for patients in diabetes care, such as in nurse-led clinics, which would meet the increasing needs arising from an increasing number of patients with T2D globally, as nurse-led clinics are seen as both clinically effective and cost effective (Arts *et al.* 2012, Bodenheimer *et al.* 2005, James 2011, Steuten *et al.* 2007, Vrijhoef *et al.* 2002).

## **Type 2 diabetes**

Type 2 diabetes (T2D), which accounts for 90% of all cases of diabetes, is a chronic disease that occurs when the functioning of the pancreatic  $\beta$ -cells progressively deteriorates, and they do not produce enough insulin. T2D can also occur as a result of metabolic syndrome (Alberti *et al.* 2006); prediabetes (Bergman 2012); and insulin resistance, which happens when the muscles and adipose tissues cannot effectively use the insulin that is produced (ADA 2012, Agardh & Berne 2010, Bergman 2012, IDF 2012a). Type 2 diabetes is a progressive disease; uncontrolled, it results in hyperglycaemia, and in turn causes damage to vessels, nerves, and other tissues, resulting in complicating microangiopathy such as retinopathy, nephropathy, neuropathy, and cardiovascular diseases (ADA 2012, Agardh & Berne 2010, Bergman 2012). T2D carries an 8%–11% higher risk for coronary heart disease, stroke, cardiovascular disease, and mortality for every 1% higher unit of glycated haemoglobin (HbA1c) (Eeg-Olofsson *et al.* 2010). Development of complications is associated with several risk factors, such as smoking, age, hypertension, sex, hyperlipidaemia, poor dietary habits, overweight, physical inactivity (ADA 2012, Agardh & Berne 2010, Cederholm *et al.* 2008, IDF 2012a), depression (Mezuk *et al.* 2008), and self-perceived permanent stress (Novak *et al.* 2013).

### *Prevalence and incidence*

More than 366 million people worldwide have diabetes, and the number is expected to rise to 552 million by 2030 (Whiting *et al.* 2011). Approximately 7 million people develop the disease every year, and it is expected to increase by 69%–92% in developing countries and 20%–25% in developed countries

until 2030, mostly due to an ageing population and physical inactivity (Shaw *et al.* 2010, Whiting *et al.* 2011). In Sweden, the prevalence of diabetes is estimated at between 4% and 7.3% (n=380,000–480,000) (IDF 2012b, National Board of Health and Welfare 2010, Shaw *et al.* 2010). In addition to the number of cases diagnosed, the number of people with prediabetes is likely to be a further 1 in 3 diagnosed, relating to symptoms that often are unrecognised for several years before diagnosis (Bergman 2012). The Swedish Council on Health Technology Assessment in Healthcare (SBU 2009) and others recommend opportunistic screening to identify individuals at increased risk of developing diabetes and those with impaired glucose tolerance (Bergman 2012).

### *Treatment*

In Europe, the St Vincent Declaration of 1989 is an agreement between representatives from government health departments and patient organisations, together with diabetes experts, to implement guidelines to reduce morbidity as well as mortality from diabetes. The declaration includes actions for medical, psychosocial, and pedagogical aspects of diabetes care (Diabetes Care and Research in Europe 1989). In treatment of T2D the primary focus is on lifestyle modification. Active and healthy living is advocated to improve insulin sensitivity and  $\beta$ -cell function. Regular and increased physical activity is recommended (National Board of Health and Welfare 2010), approximately 30 minutes of moderate activity per day or at least 150 minutes per week (Inzucchi *et al.* 2012). Furthermore, a reduced body weight and a low-fat, low- and slow-carbohydrate, and high-fibre diet are advocated (Inzucchi *et al.* 2012, National Board of Health and Welfare 2010, SBU 2010).

In medical treatment, anti-diabetic oral agents, such as metformin, are primarily recommended, particularly in cases of overweight. Sulphonylurea and other oral agents, but also insulin, are recommended when lifestyle changes and metformin no longer are enough to normalise blood sugar levels (National Board of Health and Welfare 2010). Treatment targets for diabetes are for HbA<sub>1c</sub> <52 mmol/mol, blood pressure <130/80 mm Hg, and low-density cholesterol <2.5 mmol/l (National Board of Health and Welfare 2010). Modest weight loss of 5% to 10% has been shown to contribute meaningfully to achieving improved glucose control, and therefore, establishing a goal of weight reduction, or at least weight maintenance, is recommended (Inzucchi *et al.* 2012).

### *Quality assessment*

In Sweden, the National Diabetes Register was introduced in 1996 (Gudbjörnsdóttir *et al.* 2003) and is a tool for assuring quality of diabetes care and evaluating quality indicators, including target achievement. NDR data include patient characteristics such as age and sex, and biomedical measures such as blood glucose, blood pressure, blood lipids, body weight, and BMI. By 2012 there were approximately 345,000 registered patients with T2D in the NDR, and the trend is improved cholesterol and blood pressure, and reduced smoking habits. Cases of overweight are stable but not decreasing, and physical activity seems to be declining (NDR 2012). Over a longer period, BMI has increased and been interpreted as a main cause of increased HbA1c (NDR 2012).

Patient-reported outcome measures in diabetes care are to be included in the NDR in the future, raising measures of ability to manage illness, including aspects such as experiences of service, self-management, diabetes-related activities, patient safety, and physical health (NDR 2012). Furthermore, structured routines in diabetes care are needed to improve quality at each care unit, and the care needs to be evaluated better (Wredling & Johansson 2009), which also is emphasised in national guidelines (National Board of Health and Welfare 2010).

### *Healthcare visits*

In Sweden, persons with T2D are advised to have contact with the healthcare service based on the need that exists (National Board of Health and Welfare 2010), preferably several contacts during the first year and thereafter annually, with the general practitioner and the DSN (Adolfsson *et al.* 2010, National Board of Health and Welfare 2010). The visits include laboratory tests to measure blood sugar and HbA1c, blood lipids, and microalbuminuria, and physical examinations such as for blood pressure, waist measurement, weight, and foot health. Smoking cessation should also be offered. Communication about patients' understanding of the disease and their self-management, together with patient education and support is included to encourage patients to achieve and maintain control of the diabetes, which is important for preventing diabetes complications (National Board of Health and Welfare 2010).

Group-based education programmes are recommended, both nationally and internationally (ADA 2012, National Board of Health and Welfare 2010, SBU 2009). Patient education and goal setting during the healthcare visits have been found to be checklist driven concerning individual visits, and most often group education are preplanned, with the education seldom being

adapted to the patients' needs. In addition, only one-fourth of the Swedish PHCs included the patients in the decision about biomedical goals concerning their diabetes (Adolfsson *et al.* 2010). In primary healthcare, it is recommended that diabetes care should be a team service, preferably consisting of the person with T2D, a DSN, and a GP, and also including a dietician, physiotherapist, and foot therapist when the need arises (National Board of Health and Welfare 2010, Wikblad 2012). Multi-professional teamwork in Swedish primary healthcare, viewing the provision of diabetes care as team effort, is not, however, always practised to the extent desired, (Adolfsson *et al.* 2010).

## **DSNs' and patients' views on diabetes care**

### *DSNs' perspectives*

It has been argued that healthcare professionals are too concerned with disease-oriented issues, focusing on information and biomedical test parameters (Jutterström *et al.* 2012), what has been described as a disease-over-life perspective (Zoffmann & Kirkevold 2005). Hörnsten *et al.* (2008a) described conflicting encounters in diabetes care, where DSNs experienced difficulties in being person-centred, and difficulties in being close to patients and relying on their life-world knowledge. They further described difficulty in implementing guidelines and working according to medical expertise, and simultaneously emphasising each patient's needs. In addition, patients' views of satisfying diabetes care were not always in line with DSNs' views of satisfying clinical encounters (Hörnsten & Graneheim 2011, Hörnsten *et al.* 2008a). To support patients efficiently, DSNs need knowledge about how patients learn to live and integrate the disease into their lives (Hörnsten *et al.* 2011, Jutterström 2013, Kneck 2011). Illness itself can affect patients' ability to maintain their autonomy by challenging life plans, lead to changes in relationships, and disrupt self-identities (Entwistle *et al.* 2010). To support patients' autonomy, it is for the DSNs important to take into account the patients' circumstances, preferences, and concerns when advising them, and also to enable patients to ask questions, and to ensure patients that their choices will be respected. Respecting patients' autonomy is not only about respecting and enabling patients to make well-informed decisions but also about promoting their autonomy and listening to them, emphasising the relationship, without merely focusing on narrow health gains (Entwistle *et al.* 2010).

## *Patients' perspectives*

In this thesis, I refer to and discuss interchangeably the patient in diabetes care and the person with T2D. Depending on the context, a patient is defined as a person who is in contact with healthcare professionals, to either maintain a healthy state or obtain support to manage long-term or chronic illness, and to be comforted, relieved, or cured of a disease or condition. Being referred to as a patient per se also entails certain rights, as well as invoking certain obligations on the part of professionals (SOU 2013:2, SOU 2013:44).

The patients' perspectives of T2D are important to consider when supporting them in their self-management to gain control of the disease. Some authors, though, have described a controlling style as a benefit for diabetes outcomes and for patients' health maintenance. Edwall *et al.* (2010) described the meaning of a consultation from a patient perspective and reported experiences of being controlled, feeling exposed, feeling comfortable, and feeling prepared, which was seen as a process of learning to deal with diabetes. However, it can be argued whether such a consultation can be called person-centred, since control can be seen as limiting autonomy.

It has been reported from a patient perspective that professionals do not always encourage patient autonomy, for instance, by providing patients with tools and ability regarding drug self-modification; instead, they tend to refer patients to contact with the healthcare service (Cooper *et al.* 2003). According to a review by Deledda *et al.* (2013), GPs' instructions and advice to prevent illness were of the lowest priority among patients in primary healthcare. In a meta-analysis (Gomersall *et al.* 2011), on patients' perspectives on self-management of T2D, it was reported that the self was under attack, facing a confusing array of information – sometimes more confused due to misunderstandings between patients and professionals – and procedures in healthcare settings could be seen as a threat not only to one's body but also to one's sense of self.

## *Living with type 2 diabetes*

Even though recommendations exist about the importance of supporting persons with T2D to achieve and maintain control of the diabetes, attitudes among patients and professionals differ, and influence the implementation of such support. Different attitudes corresponding to different economic, cultural, and social factors also influence how people manage to live with and control the diabetes (Torres *et al.* 2010). Getting diabetes is a developmental process involving learning to live with a chronic disease (Kneck 2011, Whittemore & Dixon 2008). The experience of living with diabetes refers to the emotional as well as the existential aspects of being ill and learning to

live with a chronic disease. It has been described as a process of illness integration, which aims to achieve an understanding of the disease and self-management as a natural part of life (Hörnsten *et al.* 2011), and to balance the demands of treatment recommendations and an individual lifestyle. The chronic illness experience over time has been variously likened to shifting sands, staying afloat, weathering the storms, rescuing oneself, and navigating life (Whittemore & Dixon 2008).

## **Self-management support**

### *Support of self-management*

Several definitions of self-management support exist in the literature. In the US national standards for diabetes care, self-management support has been described as an “on-going process of facilitating the knowledge, skill, and ability necessary for diabetes self-care. This process incorporates the needs, goals and life experiences of the person with diabetes and is guided by evidence-based standards” (Funnell *et al.* 2009). Self-management can be seen as a concept within the frame of self-care, the ability to care for one-self, including the activities to achieve, maintain or promote optimal health. In addition, self-management is the ability of the individual to manage life, treatment, and the consequences of the illness. Self-management is promoted by the level of confidence and self-efficacy in one’s ability to perform the activities needed for optimal health (Richard & Shea 2011). A meta-synthesis trying to delineate the process of self-management demonstrated that it includes three processes that focus on illness needs: activating resources, such as by managing bodily responses; becoming an expert, such as on individual and community services; and finally, living with a chronic illness, such as by integrating the illness into the person’s life (Schulman-Green *et al.* 2012).

Professionals may facilitate patients’ self-management by being aware of what processes the patients emphasise, since these vary in importance to patients, depending on the changes over time and context (Schulman-Green *et al.* 2012, Thorne & Paterson 2001). It has been stated that self-management includes some core components that need to be facilitated in the support, such as problem solving, decision-making, resource utilisation, the formation of a patient–professional partnership, action planning and behaviour change, and patients tailoring management plans to suit their needs (Lorig & Holman 2003, Zoffmann & Kirkevold 2012). However, a knowledge, attitude, and practice gap in the self-management support pro-

grammes of type 2 diabetes is argued as causing patients and professionals problems (Serrano-Gil & Jacob 2010).

In the literature, self-management support is often used interchangeably with diabetes self-management education (DSME). Patient education is about teaching or training of patients concerning their health (Coster & Norman 2009) and is supposed to provide patients with diabetes-specific information and hands-on training, for example, in blood sugar test techniques and self-monitoring (Bodenheimer *et al.* 2002). ADA's national standard for DSME describes a patient-education intervention as an exchange of knowledge, a tool, and a practice that will address the patient's needs (Haas *et al.* 2013). Self-management support focuses on problem-solving skills, and thereby, persons with T2D are supposed to take actions to improve their health (Bodenheimer *et al.* 2002). In this thesis, I have chosen to label the DSNs' education and support for persons with T2D to self-manage their illness, as self-management support.

### *Self-management support programmes*

Participation in self-management support programmes can help persons with T2D to increase their control of the illness (Murphy *et al.* 2011) and improve glycaemic control (Gary *et al.* 2003), even if results reporting effects in longer terms are divergent (Norris *et al.* 2002). Meta-analyses have been difficult to interpret, due to large variations and heterogeneity of existing programmes. Methodological issues such as length of follow-up and outcome measures have made interpretation complicated (Gary *et al.* 2003), and it is still difficult to make any assumptions about effects of patient education on patient outcomes (Coster & Norman 2009). Patient education has been conducted on different levels and in various settings with individuals and groups, and on a population level. It has been delivered face-to-face, over the Internet, via television, and as social marketing (James *et al.* 2009), as part of either an educational/behavioural approach, or an empowering, person-centred, psychosocial approach.

In earlier meta-analyses (Ellis *et al.* 2004, Gary *et al.* 2003), educational and behavioural interventions in T2D have demonstrated some improvements in glycaemic control. Face-to-face interventions, using a cognitive reframing teaching method or including exercises, have been reported more likely to improve glycaemic control (Ellis *et al.* 2004); however, this is contradicted by other authors, who argue that it is difficult to make any assumptions about the effect of self-management support programmes (Coster & Norman 2009). A meta-analysis by Minet *et al.* (2010), found that self-management interventions that have smaller sample size and a compact programme with sessions timed closely together have a tendency to be more

effective. Another meta-analysis by Pimouguet et al. (2011) reported that self-management programmes, including, for example, patient education, psychological intervention, and self-monitoring, had a clinically moderate but significant impact on HbA1c. The effective components were a high frequency of patient contact and independence to adjust treatment without physician's approval (Pimouguet *et al.* 2011). It has been reported in the DAWN study that only approximately 48% of persons with diabetes worldwide have had the opportunity to participate in self-management programmes (Nicolucci *et al.* 2013).

The outcomes of self-management support interventions have been measured using different outcomes, such as physiological measures and HbA1c, but also diabetes knowledge, self-management behaviours, psychosocial factors, and psychological variables, and pointed to a variety of effects. In a review Duke *et al.* (2009) reported that there were no evidence that individualised diabetes education compared to usual care for persons with T2D improved glycaemic control, BMI, or blood pressure. In contrast, in a systematic review of group education programmes, group-based diabetes self-management education compared to traditional care was reported as having beneficial effects on glycaemic control and psychosocial aspects such as blood glucose measurements and diabetes knowledge, which were improved up to two years after the programme (Steinsbekk *et al.* 2012). A recently published review (Hunt 2013) shows that nurses' work with patients to establish self-management goals does improve patients' outcomes in the areas of diabetes knowledge, self-management behaviour, and quality of life, as well as glycaemic control.

### *Empowerment in diabetes care*

The word empowerment stems from power, the Latin *poterè*, which means to be able and to have the ability to choose (Kuokkanen & Leino-Kilpi 2000). Empowerment is a concept widely spread in various contexts, on individual, social, and societal levels, and defining the concept is therefore difficult. A review from a multidisciplinary concept analysis of empowerment (McCarthy & Freeman 2008) reported that it is a mutual process of learning, becoming active, and accepting autonomy and responsibility, and is not dependent on management initiatives. Within the healthcare service, empowerment has been defined as being based on the assumption that for individuals to stay healthy, they must be able to bring about changes in their personal and social lives, and within the contexts in which they find themselves (Feste & Anderson 1995). Empowerment approaches are recommended in diabetes care, and Anderson and Funnell (2010) have defined the process of empowerment as the discovery of one's inborn capacity to be re-

sponsible for one's own life. People are empowered when they have enough knowledge to make rational decisions, sufficient control and resources to implement their decisions, and the experience to evaluate their actions. Empowerment is both a process and a goal for people to take control over their own lives and to discover and use their ability to gain mastery over their diabetes. Empowerment is viewed as a positive concept, referring to solutions and associated with growth and development. Professionals in healthcare can only facilitate empowerment; they cannot create or give empowerment to others (Anderson & Funnell 2010). An empowerment approach is based on a close and trusting relationship between professionals and patients. Empowerment can be reflected towards compliance, which could aid in better understanding empowerment. It has been argued that compliance-oriented healthcare reduces patients' autonomy. In such a healthcare tradition, professionals attempt to persuade and encourage persons with chronic illness, explicitly or subtly, to accept self-management goals set by healthcare professionals. In contrast, empowerment seeks to extend the patient's choice of freedom and simultaneously to strengthen patient autonomy (Falk-Rafael 2001, Feste & Anderson 1995).

Empowerment is based on the philosophy that human beings have an ability to make choices and are responsible for the consequences of their choices (Feste & Anderson 1995). Methods to support empowerment are use of questions, use of a language describing behaviours, and use of storytelling. Questions have the power to move people along their journey, while answers may stop the process of searching. Behavioural language concerns the words for activities such as describing, defining, and deciding, which could encourage people to make choices and take action. Storytelling has the power to stimulate reflections on values, beliefs, and inner strength (Feste & Anderson 1995). In a review (Aujoulat *et al.* 2007), it has been reported that the process of an empowerment approach is not necessarily disease specific; rather it aims at reinforcing or developing skills to handle situations, such as self-management. It is patient-centred and based on experiential learning, and the relation between patients and professionals needs to be continuous and self-involving by both parties (Aujoulat *et al.* 2007).

Despite the fact that an empowerment approach is recommended in diabetes care, it has not fully been accepted among professionals, and compliance approaches are still common in this area (Adolfsson *et al.* 2004, Anderson & Funnell 2010). Barriers to empowerment experienced in diabetes care are lack of time, resources, and training, although advantages of empowerment are reduced workload, improved skills of professionals, and rational service for those in need, which might improve care and facilitate involvement of persons with diabetes (cf. Anderson & Funnell 2010). A criticism of empowerment is that the approach could be used to empower people to make the right decisions, but from a healthcare point of view (Powers

2003), and empowerment does not automatically entail having the ability and resources to act and change. Asimakopoulou et al. (2012) argued that healthcare professionals have to learn by observation how empowerment works, before advocating it. Patient empowerment can also be seen as complementary to patient-centred care and can be achieved by focusing on patients' personal needs (Holmström & Röing 2010).

## **Person-centred diabetes care**

### *The concept*

In this thesis, the concept *person-centred care* is used interchangeably with *patient-centred care*, which is a term more commonly used in the literature on diabetes care. Patient-centred care was in the beginning conceived as a challenge to disease-oriented care, which could limit the person by focusing on the disease and the diseased body, and sometimes also objectified the individual (Hansson Scherman & Runesson 2009, Mead & Bower 2002). It has been argued that patient-centred care compared to person-centred care has in view a more biomedical approach set by healthcare professionals, and that the term *patient* derives from a biomedical paradigm (Ekman et al. 2011). To complicate matters further, various terms are used in the literature (Hughes et al. 2008). For example, patient-centred care (Lutz & Bowers 2000, Swedish Agency for Health and Care Services Analysis 2012), client-centred care (Falk-Rafael 2001), patient-focused care (National Board of Health and Welfare 2011), person-centred care (Edvardsson et al. 2008, Ekman et al. 2011), and person-focused care (Starfield 2011) are all concepts whereby the relationship is emphasised. They describe how to care for the patient, employing good human values, to improve health while maintaining respect for a person's individual needs.

Whatever the term used, there are similarities among them, and the use depends commonly on the context in which the care is conducted (Hughes et al. 2008, Morgan & Yoder 2012, Starfield 2011). Regardless of the labelling in the literature and despite the fact that I in the four articles within the thesis have used the concept patient-centred, I henceforth in the thesis refer to person-centred care (PCC). The commonalities of the concepts are that they relate to values such as respect for people's needs, values, preferences, and priorities; good communication; relationship building; and shared responsibility in which experiences from life-world perspectives and professional perspectives are considered (cf. Ekman et al. 2011, Hughes et al. 2008, Lepage et al. 2007, McCormack et al. 2010, Mead & Bower 2002, Morgan & Yoder 2012, Slater 2006, Starfield 2011).

### *Person-centred care in practice*

Person-centred and empowerment approaches, aiming to improve patients' decision-making and self-management and to improve quality of life, are recommended in diabetes care (Haas *et al.* 2013). Swedish diabetes care is still commonly based on a traditional, hierarchical care model deriving from acute hospital care. In general, it means that persons with diabetes are supposed to follow information and advice from professionals and are perceived as adherent or not, based on how recommendations are followed. In a hierarchical acute care model, expectations of compliance or adherence are argued to dominate the current attitudes of the healthcare services professionals, which is an approach, insufficient in diabetes care (cf. Anderson & Funnell 2000), because persons with T2D are dependent on their own decisions concerning their self-management (Funnell & Anderson 2000, Wikblad 2012). Robinson *et al.* (2008) concluded in a review that even though professionals often described their work as person-centred, patients might lack the same experience.

In the worldwide DAWN study of diabetes care (Nicolucci *et al.* 2013), the availability of person-centred care and support for active involvement was rated as low. Ekman and co-authors (2011) have argued that established routines in care are important for initiation, integration, and safeguarding of PCC in daily clinical practice. They have also argued that, despite the interest of healthcare professionals in person-centred values, these are seldom prioritised. Although healthcare professionals try to advocate for taking into account the person in the care, they often fail to implement it in practice, often referring to time constraints (Adolfsson 2008, Anderson & Funnell 2010, Ekman *et al.* 2011, Zoffmann & Kirkevold 2012). However, highlighting the person in the care and their personal needs is not something that should be practised only when time allows for it (Ekman *et al.* 2011).

### *Person-centred care interventions*

Person-centred interventions imply flexibility, and focus on delivery and communication to achieve understanding of persons with illness, to meet them where they find themselves, and to follow their agenda, developing a mutual relationship (Lauver *et al.* 2002). The effects of PCC have previously been insufficiently explored to provide evidence (Mead & Bower 2002). However, in a current systematic review (Olsson *et al.* 2013) of randomised or controlled person-centred care interventions it was reported that, despite the efficacy of PCC interventions having only been studied to a limited extent, PCC as an intervention was shown to be successful in a majority of the studies (Olsson *et al.* 2013). The results suggested a variety of positive

outcomes, such as improved interactions and relationships between patients and professionals, also emphasised in a dissertation by Wolf (2012), although the effects need to be further investigated (Olsson *et al.* 2013). A meta-analysis of PCC training interventions for professionals in a variety of clinical contexts (Dwamena *et al.* 2012) showed that training professionals in a person-centred approach aimed at improving their ability to share control with patients about topics and decisions addressed in consultations was largely successful in teaching providers new skills. The authors of the analysis concluded that interventions emphasising PCC within clinical consultations appeared to lead to significant improvements in care. The results showed positive effects in professionals' satisfaction, and indicated that PCC consultation had an impact on patient health behaviour (Dwamena *et al.* 2012).

In diabetes care, it has been stated in a review (Seitz *et al.* 2011) that interventions in primary healthcare that focus on professional and organisational aspects of diabetes care and are person-centred are most successful in influencing patients' clinical outcomes such as HbA1c. PCC interventions have resulted in improved HbA1c and/or blood lipids (Dijkstra *et al.* 2006, Hörnsten *et al.* 2008b), as well as increased diabetes knowledge among patients (Adolfsson *et al.* 2007), and increased adherence to medical prescriptions (Sahm *et al.* 2011). Hörnsten's dissertation (2004) included an intervention, based on findings by Hörnsten *et al.* (2004, 2005, 2008a), that highlighted the meaning of patients' personal understandings and integration of illness for self-management. This has been further reported to have beneficial effects on patients' HbA1c in a more recent dissertation (Jutterström 2013).

## **Rationale for the thesis**

Swedish diabetes care and particularly patient education needs to be developed, since established treatment targets are not being reached to the extent desired. Reasons for this may be that persons with T2D are struggling to reach treatment goals or that these goals are not sufficiently communicated, and that they, possibly because they are set by healthcare professionals, are not always agreed upon by the patients who are expected to fulfil them. DSNs have a key position in support of self-management, which is seen as a cornerstone in T2D treatment. However, how self-management support should be conducted is not clearly defined. DSNs are encouraged to use a person-centred approach to enhance empowerment and improve self-management among persons with T2D. In clinical practice, person-centred care has demonstrated positive outcomes for patients, although it has also been reported from a professional perspective that it is difficult to adapt to a person-centred approach. Therefore, it is of importance to get increased knowledge about the practice and implementation of person-centred care, to observe the interaction between the DSN and patients in support situations, and to explore the role of the DSNs' profession.

## **Aims**

### *Overall aim*

The overall aim of the thesis was to explore the professional role of diabetes specialist nurses in primary healthcare and to describe their experiences of person-centred diabetes care.

### *Specific aims*

The specific aim for each study was as follows:

**Study I:** To explore diabetes specialist nurses' perceptions of their professional role in diabetes care.

**Study II:** To explore diabetes specialist nurses' perceptions of their role in terms of clarity, conflict, and other psychosocial work aspects.

**Study III:** To explore the interaction between diabetes specialist nurses and patients with type 2 diabetes during group sessions about self-management within a patient-centred intervention.

**Study IV:** To describe diabetes specialist nurses' experiences with practising patient-centred care in a type 2 diabetes intervention.

# Methods

## Methodological assumptions

A qualitative approach in nursing research makes it possible to describe and interpret human phenomena (Streubert & Carpenter 2010). The ontological perspective in qualitative research in this thesis is guided by the assumptions that I as the researcher am a part of the context and in interaction with others co-create the world (the findings) by interpreting it from various points of view. Within the qualitative tradition, there are several possible interpretations, and all can be valid, even if they are different. This means that there is not one sole truth, but several, due to subjective descriptions (Polit & Beck 2013). In qualitative research, the world is seen as complex, context dependent, and interpreted from the prevailing personal history, conditions, and culture. Within the epistemology of qualitative research, the text gets its meaning (inductive and deductive) out of the reader's understanding (Krippendorff 2004). While living, it is possible to understand the world from different angles; a single explanation is not in sole control, and one often meets others with different views of the world and existence than one's own. According to Krippendorff (2004), a text never implies one single meaning, just a probable meaning from a particular perspective.

Different possible explanations have to be considered while doing research among DSNs, and in exploring interactions between DSNs and persons with T2D. In qualitative research methods such as qualitative content analysis, the focus can be to illustrate as many variations as possible of the matter under study, independent of how many utter a certain opinion. The trustworthiness of findings is achieved by thorough discussions within the research team (Graneheim & Lundman 2004, Streubert & Carpenter 2010). According to the ontology of quantitative tradition, though, there is an attempt to find the objective truth as nearly as possible. According to its epistemology, the knowledge is retrieved by a deductive approach when analysing the purpose to answer a hypothesis and/or find explanations. When using hypothesis testing, there is an assumption that the findings in the analysis represent results for the entire population and that it is possible to generalise results. In quantitative research methods such as statistical analysis, the aim is to collect data to make calculations, where validity and reliability are supposed to be achieved (Polit & Beck 2013).

To explore and describe the DSNs' professional role, I used focus group interviews (study I), and in addition, explored it by the use of a questionnaire (study II). To explore the DSNs' experiences of practising person-centred care, observations (study III) and interviews in focus groups as well as individual interviews were carried out (study IV).

## The DIVA 2 project

The data in this thesis were collected within the DIVA 2 project, evaluating the effects of an intervention consisting of patient-centred support in type 2 diabetes (Hörnsten 2004). The DIVA 2 project has two focuses, one on DSNs' experiences, which will be reported in this thesis, and one on patients' experiences and patient outcomes, reported in another thesis (Jutterström 2013). The intervention took place during 6–9 months in 2009–2010, and included nine PHCs in Västerbotten and one PHC in Västernorrland, Sweden, the latter only including a control group of patients. The patients in Västerbotten were randomised into either individual or group support sessions, or into a control group. All patients received their regular check-ups with their regular GP or DSN. The DSNs included in the intervention were a purposeful sample, because they were working at the PHCs included and volunteered to participate in the intervention. The participating DSNs held six 1- to 1.5-hour sessions directed towards persons with T2D, designed to be person-centred and focusing on personal understandings of diabetes (Hörnsten *et al.* 2004).

In preparation for the intervention, the participating DSNs received a 20-hour workshop led by the research group, including theoretical education in various perspectives on diabetes and practical training in person-centred support with the aim of supporting illness integration and self-management. The DSNs participated in role-plays of dialogues aimed at highlighting motives for change and supporting decision-making, taking ambivalence into consideration. In connection to the role-plays, the DSNs had opportunities to reflect upon their professional role and about different perspectives on disease/illness. The DSNs were trained to discuss patients' views on the image of the disease, including severity, the meaning of getting a diagnosis, the integration of illness over time, the space for self-management, their views on responsibility for self-management, and lastly, their future prospects when taking their illness into consideration. The six issues were themes of the six planned sessions as a part of the intervention and had previously been identified as important in personal understandings of T2D (Hörnsten *et al.* 2004). After the preparatory workshop, the DSNs were expected to lead support sessions organised as individual or group support for patients with T2D. The six issues described above were themes the DSNs were requested to emphasise, since these were seen as reflecting patients' understandings of T2D. However, patients were to be encouraged to discuss everything they wanted, related to their experiences of having T2D.

## Design and settings

This thesis has a descriptive design, including an intervention. Methods with qualitative and quantitative approaches were used. The studies were performed in County Council-governed primary healthcare settings in Västerbotten and Västernorrland in northern Sweden. An overview of the studies is given in Table 1.

*Table 1. Overview of studies, design, participants, data collection, and analysis*

<b>Studies and status</b>	<b>Design</b>	<b>Participants</b>	<b>Data collection and period</b>	<b>Analysis</b>
<b>I Published</b>	Qualitative	29 DSNs	Focus group interviews 2009	Qualitative content analysis
<b>II Accepted</b>	Quantitative Cross-sectional	31 DSNs	Questionnaires 2010	Descriptive comparative statistics
<b>III Submitted</b>	Qualitative	10 DSNs 44 persons with T2D	Observations 2010	Qualitative content analysis
<b>IV Submitted</b>	Qualitative	10 DSNs/ 6 DSNs	Focus group/ individual interviews 2010–2011	Qualitative content analysis

## Participants

Study I included a purposeful sample of 29 DSNs, with an average age of 51 years, working at 23 different primary healthcare centres in Västerbotten and Västernorrland. All were registered nurses working as primary healthcare nurses with responsibility for diabetes clinics at their PHCs. Their work experience as nurses ranged from 15 to 41 years, and as DSNs from 2 to 19 years.

Study II included a sample of 45 available DSNs in Västerbotten's County Council, of whom 31 (69%) agreed to participate. Their median age was 56 years (range 34–63). Twenty-six (84%) had either a university or college degree, while five (16%) had a higher university degree. A majority (n = 30, 96.8%) were permanently employed. Most of them (n = 26, 83.8%) worked 75%–100% (31–40 hours/week). Their average work experience at their current workplace was 16.0 years (SD 12.91), and their experience of responsibility for diabetes care on average was 13.0 years (SD 7.43). The time they spent on DSN work ranged from 20%–100% of their total working time.

Study III included participants in the intervention. The samples consisted of 10 DSNs (all women), and 44 persons (29 men, 15 women) with T2D. The DSNs' median age was 56 years (range 33–63), and they worked at nine different PHCs in Västerbotten County. Inclusion criteria for the DSNs were being a registered nurse and working as a primary healthcare nurse with responsibility for diabetes clinics at their healthcare centre. Eight DSNs had a postgraduate education in primary healthcare nursing, one in medicine and surgery, while one lacked a postgraduate education. Nine of them had a university education in diabetes care, while the tenth had gone through a diabetes course offered by a pharmaceutical company. The persons with T2D were aged between 45 and 76 (median 64) years. They had 4–21 (median 9) years of experience of diabetes care. Inclusion criteria for patients were being diagnosed with T2D within three years, Swedish speaking, and having no cognitive impairment or severe illness other than T2D, such as cancer in a last stage.

Study IV included the ten DSNs described above in study III. All ten participated in focus group interviews, and six of them participated in individual interviews.

## **Data collection**

### *Focus group interviews*

Focus group interviewing is frequently used in qualitative health research (Morgan 1997). It is a suitable method of collecting data regarding people's views and attitudes, since it clarifies experiences and problems with specific topics in groups of participants (Morgan 1997, Morgan & Bottorff 2010). Interaction between the participants is integral to the method, and all participants are considered as active persons within the group. There is no single right way to do focus group interviewing; hence new technologies and new research questions continue to explore and develop new ways of interviewing (Morgan & Bottorff 2010). There is no appropriate number of participants required to be involved in a focus group, besides at least three, including the moderator. Although the size of a focus group does influence the outcome, smaller focus groups can have benefits due to the intimate atmosphere (Morgan 1997, Morgan & Bottorff 2010, Toner 2009). Morgan and Bottorff (2010) have stated that in focus groups, differences among participants rather than numbers of participants correspond to larger variation in the data. The focus group interviews were performed when DSNs were gathered together in DSN conferences (study I) or meetings prior to the intervention (study I), and when the intervention was

finished (study IV). The role of the interviewer was to maintain the focus of the interview, to encourage broader discussions when divergent opinions occurred, and to get the participants to reflect on specific topics. A co-researcher participated in the focus group interviews and made notes during the interview to make sure that all topics were included according to a semi-structured question guide. Examples of questions were “Can you please describe your own part in diabetes care?” “What expectations do you think others have of you?” and “How do you regard yourself as a DSN?” The interviews took place at healthcare centres or conference centres and lasted between 50 and 90 minutes.

### *Individual interviews*

Individual interviews are the most widely used data collection method in qualitative research; they allow participants to express their individual experiences and reflect their personal realities. Individual interviews are described as yielding in-depth data, such as personal perceptions and experiences of a specific matter (Carolan 2003). The purpose of the individual interviews (study IV) was to collect in-depth data following focus group interviews. The individual interviews were performed within six months after the intervention was finished. We considered that individual interviews could enrich the data by adding more and in-depth data such as personal perceptions and experiences, and thereby avoid expressions of group thinking. The interviews were semi-structured, and open-ended questions were used, following an interview guide. In the individual interviews the focus was on encouraging the participants to talk about their experiences of practising person-centred care during the intervention. The participants were asked and encouraged to speak openly about their experiences, and examples of questions were “Can you please tell me more about participating in the intervention?” and “How has it influenced you to practise a patient-centred approach?” As an interviewer, I asked probing questions such as “Can you please tell me what it means for you?” and “Can you please expand on that?” The interviews lasted between 26 and 50 minutes.

### *Observations*

In participating observations (study III), the observer role is integrated, which is described as a participant-as-observer approach (Adler & Adler 1994), since the observed patients and DSNs were conscious of the observer’s role as a person doing research. Ten observations (study III) were performed during patient support group sessions. The group sessions consisted of 3–6 patients and one DSN. The observations were performed on the fifth out of

six planned sessions, the theme of which was patients' views on responsibility for self-management. The sessions were audiotaped, and field notes were written by me, as the observer. Through the observations, the interaction could be explored. The observation focused on the interaction, actions, and reactions during the group sessions. The rooms for the group sessions varied from large conference rooms with track lighting in the ceiling, to rooms decorated in a home-like style, or small "storage-like" rooms without windows, except from a glass door out to a corridor. Despite the different environments, the observer had a good overview of the participants during the different occasions, and the audiotape-recorded material was captured, transcribed, and included in the observational data.

### *Questionnaire*

The Nordic Questionnaire of Psychological and Social Factors at Work (QPS-Nordic) (Dallner *et al.* 1999, Dallner *et al.* 2000), developed in 1999, assesses various aspects of the work environment and takes into account the continuing evolution and change in organisations. It also includes the innovative climate, which is an important component of a learning organisation (Dallner *et al.* 2000). The QPS-Nordic is a broad instrument based on theories and conceptual models of organisational behaviour, work motivation, and job satisfaction, as well as theories of job stress, well-being, and health. It consists of 118 items, of which 80 form 26 subscales, and which were the units of analysis. The items are scored on a 5-point scale where a higher value represents higher agreement, and represent the degree of contentment at work at task, individual, and social/organisational levels. The questionnaire has previously been used among healthcare professionals (Jönsson 2011) and been found reliable (Cronbach's alpha 0.61–0.87) (Dallner *et al.* 2000, Wännström *et al.* 2009). Data from a reference group of healthcare professionals (n=102) are presented in the QPS-Nordic manual (Dallner *et al.* 1999), and these were used for comparisons with our data. In this study, the subscale work centrality was excluded, since there were no data originating from the reference group. Complementary descriptive data were requested and added to the QPS-Nordic instrument, such as gender, age, education, employment, working hours, work experience, and experience of health promotion.

## **Data analysis**

### *Qualitative content analysis*

Qualitative content analysis (studies I, III, & IV) is a method to analyse communication in a systematic manner (Krippendorff 2004). The analysis is a process of interpretation that focuses on similarities and differences between different parts of the text and results in the organisation of the data into categories or themes. Qualitative content analysis is not a linear process, but moves forward and backward between different levels of data. This is an analytical process where the preliminary findings such as codes, categories, or themes, by comparisons and discussions, lead to agreements of interpretation within the research group (Graneheim & Lundman 2004). The text is divided into meaning units, which are condensed, interpreted, and labelled with codes describing the content. The codes are compared for similarities and differences and organised into groups of data with similar content, which are abstracted into categories or themes – a higher level of understanding (Graneheim & Lundman 2004). The transcribed text in studies I, II, and IV was analysed by means of qualitative content analysis described by Graneheim and Lundman (2004). The analysis was performed in several steps. First, the interviews and the transcribed text from the observations were read through to gain a sense of the whole. Second, the text was divided into meaning units corresponding to the aims of the studies, and condensed when needed, while preserving its core. Third, the condensed meaning units were coded and compared for similarities and differences, and thereafter grouped into tentative categories or themes on various levels. Finally, threads of underlying meaning were identified and labelled as main themes. Over time, the analyses in the different studies developed from being close to the text such as in study I, to make more abstract interpretations in studies III and IV. To ensure trustworthiness throughout the analysis, the research group discussed codes, categories, subthemes, and themes until agreement about labelling was reached.

### *Statistics*

Descriptive statistics were used in study II to describe aspects of DSNs' professional role with the use of a questionnaire. For the analysis, SPSS version 18.0 (SPSS Corp, Chicago, IL, USA) was used. If <10% of the items within a subscale were not completed, missing values were replaced with mode values. It was decided that, if >10% of the items within a subscale were missing, data had to be excluded, but this provision was never needed. Data are presented as means with standard deviations. Since data from the refer-

ence group consisted of mean values, one-sample *t*-tests were used to test for differences between the groups. Variables from the QPS-Nordic and descriptive data were tested for correlations using Pearson's correlation coefficient (*r*). A *p*-value of <0.05 was considered statistically significant.

## **Ethical considerations**

The research was approved by the Regional Ethical Review Board in Umeå (Dno 06-126M). Information about the studies was given to the head of primary healthcare and the local primary healthcare centres' managers. The participants were invited and informed about the study by letter, by telephone, or in person (study I), or in person and by letter (studies II, III, & IV). The DSNs had to sign an informed consent for participation, which also was supported by their managers at each PHC concerning the intervention (studies III & IV).

The patients received written information about the research project from the research team and signed an informed consent to participate. Before each study was performed, the participants were informed once again about the purpose of the study. The patients participating in the observations of group sessions got repeated information in advance that a researcher would attend as an observer at the next session. The participants were informed that participation in the studies was voluntary and that they could decline or drop out at any time without giving any reason.

The results are presented at group level to avoid identification, and based on current ethical practices, confidentiality and de-identified presentations of the participants' quotes were assured to protect their integrity. Because of possible emotional reactions in the interviews, the research team were prepared to handle such situations, but no such reaction was observed. Risks of the project, such as privacy infringement with the risk of violation, were assessed as low, while the benefits – to improve the diabetes care – were seen as high.

# Results

## A complex professional role

The findings demonstrated a complexity in the DSNs' role, since they were supposed to fulfil several challenges from, and expectations of, not only patients and colleagues but also themselves (study I). The findings demonstrated that the professional role included striving to fulfil expectations simultaneous with handling several ambiguous challenges. This complexity was also found in study II. The findings demonstrated that the DSNs perceived high job demands, and that role clarity as well as role conflict correlated significantly with different psychosocial aspects of work (study II).

### *Multifaceted profession*

The DSNs perceived their professional role as quite demanding, having several expectations to fulfil. The findings resulted in five themes: striving to be an expert, striving to be a fosterer, striving to be a leader, striving to be an executive, and striving to be a role model (study I). Within the themes, challenges and difficulties were expressed, which were interpreted as ambiguities for the DSNs.

Striving to be an expert included being a teacher and a specialist. The DSNs had expectations upon them to educate persons with T2D to self-manage their illness, and described themselves as competent, qualified, and decisive, managing most situations of diabetes care independently. Despite being experts, the DSNs perceived that they had a lack of time and few occasions themselves for continuing education. Simultaneously, they were aware that patients had a lot of updated diabetes knowledge that they sometimes had problems meeting. When they tried to maintain the expert role, they also described themselves as less skilled and uninformed (study I).

Striving to be a fosterer included being a counsellor, a monitor, and a supervisor. The DSNs motivated the patients to make lifestyle changes, controlled the patients' daily lives and sometimes made decisions about the patients' future care. Striving to be a fosterer meant having doubts about whether persons with T2D had the ability to make lifestyle changes, and the DSNs considered that strengthening their motivation was time consuming. The DSNs sometimes mistrusted the patients and expressed frustration with their lack of willingness to change lifestyles, and thereby resigned themselves to supporting the patients.

Striving to be a leader included being an authority and a coordinator. The DSNs were responsible and reliable about organising and coordinating the diabetes care. Being a leader meant that they, despite all the difficult situations they were expected to solve, were subordinate to the GPs, and they described being overwhelmed by their responsibilities. They expressed it as a challenge to coordinate and remain organised without becoming exhausted.

Striving to be an executive included being a bureaucrat and being an administrator. The DSNs worked according to guidelines, used quality registers, and gave practical service to patients and GPs as well. Striving to be an executive also meant being uncomfortable and insecure in the clinical encounters, since they were torn between several tasks at the PHC, which made them fragmented in their work performance. Finally, striving to be a role model included being healthy, being available, and being engaged. They described themselves as healthy, and being available for others' safety and their engagement made them committed to all patients. Being a role model meant having high standards that were difficult to fulfil. Being healthy was also described as wishful thinking. Unavailability meant self-reproach and doubtfulness about their ability to support self-management among persons with T2D (study I).

### *Demanding psychosocial aspects of work*

Results from study II showed that the DSNs in general scored significantly higher on quantitative demands, decision-making demands, and learning demands than a reference group of health professionals. The DSNs also scored significantly higher on positive challenges at work, commitment to the organisation, extrinsic work motivations, and human resource primacy. They scored predictability for the next two years and support from friends and relatives as significantly lower in comparison with the reference group. A correlation between role expectations such as role clarity and role conflict and other psychosocial factors was analysed. The results demonstrated a significant positive correlation between role clarity and work experience of health promotion, perception of mastery, support from co-workers, and empowering leadership. The result also demonstrated a significant positive correlation between role conflict and quantitative demands and learning demands.

### *Summary of the complex role*

The results from the qualitative study (study I) and the quantitative study (study II) to some extent reflected each other. The DSNs described difficulties in living up to expectations from both patients and colleagues, and from

themselves (study I), an important aspect that made the role performance complex. Lack of time was a constantly repetitive circumstance, which had an impact on the complexity of the role. Motivating patients was seen as time-consuming, furthermore the DSNs were being torn between several tasks, and were overwhelmed by responsibility (study I), something that was reflected in the questionnaire as high quantitative demands (study II). Being decisive in problematic situations was another circumstance that was described several times as challenging (study I). However, no significant differences between the DSNs and the reference group were found concerning decision-making demands (study II). The DSNs several times described a need for continued education to update and maintain knowledge to support persons with T2D (study I), which was reflected in the fact that the DSNs perceived significantly high learning demands (study II). Positive challenges were significantly higher among the DSNs (study II), and having positive challenges at work was pronounced as important, which was interpreted as that the DSNs' profession was experienced as exciting and challenging (study I). Expressions of loneliness and lacking support (studies I & II) need to be addressed, and it was indicated that for the DSNs' professional development and role clarity it was of importance, to have support from colleagues and managers, and also continuing education.

## **A challenging person-centred intervention**

The exploration of DSNs in the person-centred diabetes care intervention demonstrated that, when practising PCC in the interaction with persons with T2D, PCC was not an obvious focus (study III). The DSNs described practising person-centred care as challenging the accustomed and traditional way of working, which meant facing an altered professional role (study IV).

### *Empowerment or authority struggle*

The interaction was a dynamic process where three themes varied from “becoming empowered” to “approaching each other from different perspectives” to “struggling for authority” (study III). The theme “becoming empowered” was characterised by empowerment of both DSNs and patients in the interaction. Through engagement, enabling, relating to one another, and sharing each other's views of patients' self-management, they contributed to the interaction, and they saw each other as partners in the care of the diabetes. The interaction was characterised by a person-centred approach and empowerment in which both parties were strengthened, and the interaction about self-management was facilitated. In the theme “approaching each

other from different perspectives”, the interaction was characterised by the DSNs and patients discussing diabetes from the different perspectives on disease vs. illness. The interaction included objectifying and individualising, focusing on facts and emotions. The interaction was characterised by an effort to engage with one another and by striving to listen to each other’s perspectives, though commonly without succeeding to reach and understand each other. The theme “struggling for authority” reflected an interaction that was interpreted as DSNs’ governance, justifying their actions, while patients became subordinated. However, when the DSNs became vague, the patients became more directive and took over in the interaction. The struggle between them, both trying to grasp the position of authority, made it difficult for the DSNs to support and enhance patients’ self-management. In such cases, the interaction was interpreted as neither supportive nor facilitating for patients’ self-management (study III).

#### *An altered professional role*

Practising person-centred care was described by the DSNs as facing an altered professional role, including ambivalence. Simultaneously, they described that with practice they gained an enriched relationship with patients (study IV). The main theme, “an altered professional role”, reflected that by practising person-centred care, the DSNs faced a possibility of a new position, and to some extent a new approach and new routine, increased knowledge, courage, and engagement. Simultaneously they described how, by practising person-centred care, the prevailing and accustomed way of working was challenged (study IV). The theme “ambivalence about practising person-centred care” reflected the struggle between being content in a well-established role and at the same time being challenged to adopt an alternative way of interacting with patients. The theme described their ambivalence about a withdrawn position of diabetes expertise, inconvenience about changed routines, and views of PCC as difficult but possible (study IV). The theme “enriched relationship with patients” reflected that their relationship with the patients was deepened when they became aware of the importance of talking about life and the severity of the disease. Patients’ narratives made the DSNs more engaged in patients’ life-worlds, which entailed a closer relationship (study IV).

#### *Summary of a challenging person-centred intervention*

The results from the two qualitative studies concerning the challenging person-centred intervention were reflected within one another. The observations revealed an interaction that in parts was strengthening and em-

powering for patients' self-management (study III). The DSNs described how, by emphasising matters important to patients, a closer relationship was achieved (study IV), which could be strengthening for both the DSNs and the patients. When the interaction was less person-centred, it implied a struggle for authority for both the DSNs and the persons with T2D (study III). The DSNs' attempts to adopt a new, alternative role simultaneously meant being insecure in their professional role (study IV). In between the two poles of more or less PCC, the interaction was characterised by each party emphasising their perspective on illness and disease (study III). This challenge of implementing PCC was also reflected in the DSNs' views of PCC as difficult but possible. Despite ambivalence, the DSNs described the benefits of a closer relation with patients in diabetes care, seeing them as people with personal needs, and PCC as a means for developing their ability for self-management support (study IV).

## **Discussion**

This thesis shows that the DSN's professional role is both challenging and complex, with high expectations and demands to fulfil. Practising person-centred care was possible, although difficult to carry out. The comprehensive interpretation of the results of the four studies is that the relation between DSNs and persons with T2D is characterised by proximity and distance. This can be understood from a caring perspective, since I apprehend caring as embedded in the DSN profession and as the essence of nursing. Furthermore, I have interpreted that a power perspective prevails in diabetes care, since the DSN has professional responsibilities to fulfil, while persons with T2D more or less are in a position of need, due to their illness. Person-centred values are mirrored, since PCC in diabetes care is a recommended approach (ADA 2012, IDF 2012a, Haas *et al.* 2013). The professional role of DSNs will be reflected vis-à-vis a caring relation, power relations, and a person-centred relation. Furthermore, the discussion will be summarised in a paragraph about proximity and distance in the relationship of DSNs and persons with T2D.

### **Proximity and distance in the interpersonal relation**

#### *A caring relation*

The caring relation in the three studies (I, III, & IV) was characterised by proximity, either ongoing or desired. McCance *et al.* (1999) highlighted

caring both as a philosophical concept and as a concept focused on actions, activities, and care provision. Roach (1992), for instance, defined caring by means of the five “C”s. Roach mentioned compassion, competence, confidence, conscience, and commitment as important aspects of caring. Three of these concepts, compassion, confidence, and conscience, may reflect proximity in the caring relationship. Compassion is described as being aware of one’s relationship with others, responding to the experience of another, being sensitive to others’ vulnerability, and being present to share and make room for the other. Confidence is described as a quality that fosters a trusting relationship, which may empower others to reach their desired goals. Conscience is described as a moral compass or a state of moral awareness, highly needed in a caring relationship (Roach 1992). By reflecting on caring aspects and core values such as trust, nearness, sympathy, support, knowledge, and responsibility, nurses could be encouraged and inspired (Snellman & Gedda 2012), leading to professional development and a qualitative caring relationship.

The results (study I) revealed that the DSNs wanted to relieve patients and colleagues, having the best for them in focus. The DSNs expressed a wish to be a support for patients and offer them diabetes competence while caring for them, which can be interpreted as a desire for proximity. A caring relation was also observed in the interaction leading to empowerment (study III). In this interaction, the two parties met each other authentically; they mutually shared experiences about T2D and accepted and confirmed each other’s different perspectives and expertise from the fields of diabetes and the patients’ life-world experience (cf. Buber 1994). According to Norberg and coworkers (1992), a caring relation exists when both parties focus on the task as the goal for the relation, and the problems that should be solved, such as self-management. In such situations the relation itself between the DSN and the person with T2D can be seen as the medium in which the professional can help the patient in their lifestyle changes and in responsibility for self-management (cf. Norberg *et al.* 1992).

A caring relation, however, is not always simple and obvious, such as when two parties are unfamiliar with each other and the task is difficult and the context problematic. Such problems were identified in the observations, when the interaction about self-management between DSNs and persons with T2D sometimes ended up in a struggle for authority (study III). According to Norberg and coworkers (1992), an initial phase of adaptation may include testing of the relation, instead of focusing on the task.

The results (study II) also showed that the DSNs scored high work demands, something that might obstruct the caring relationship. Pouwer *et al.* (2006) argued that professionals who perceive a heavy workload in their work often avoid discussing emotional subjects in the clinical encounter. For example, they found that among patients with high levels of emotional

problems related to their social support and T2D, in only a fifth of the medical charts were these problems mentioned. The authors state that recognition of emotional problems needs to increase among professionals working in diabetes care, also emphasised by other (Furler *et al.* 2008). Highlighting and reflecting on problems relevant for the persons with T2D, such as listening to and discussing disease severity and other emotional and social problems, could also enrich the DSNs' relation to patients (study IV). The importance of problematizing patients' emotions and problems was also highlighted by Snellman (2001), who argued that emotional problems could be reduced by communication with professionals in a caring relation. Proximity is argued to be vital for nurses to understand patients, to act on their behalf (Torjuul & Sorlie 2006), and to support self-management. A close relationship in diabetes care is thereby vital for patients and for their adherence to management plans (Stubbs 2007). The importance of a close relationship for satisfaction with care has also been described from a patient perspective (Deledda *et al.* 2013, Hörnsten *et al.* 2005).

My assumption is that a caring relation must include proximity. In order to establish proximity, an interpersonal relation is necessary. This is in line with the philosopher Martin Buber's (1878–1965) (Buber 1993, 1994, 1997, 2011) writings about the interpersonal relation. Buber (1994) clarified that there is a distinction between the "I and You" and "I and It" relationships, where the term "I and You" describes a relationship in a mutual existential meeting in which neither party imposes one's own ideas, qualifications, or objectifications on the other. In this relationship, a true subject can exist. On the other hand, a relationship can be more superficial, when "I" interacts with other people and sees them as objects. If the DSNs include earlier experiences and preunderstandings in the encounter or give fixed information, there is a risk of objectifying the person with T2D. Such a relationship cannot develop and stops at, as Buber described it, an "I and It" relation. An authentic relationship can only be built when both parties accept each other and confirm the other as a "You" (Buber 1994, 1997, 2011). This relation is built neither within each person nor in both; the relation is built in the interpersonal, what is real between them. In this relationship the person needs to accept oneself and the other each as unique persons contributing themselves (Buber 2011). It is important to remember that DSNs meet persons with T2D only briefly and intermittently during their lives (approximately 1 hour per year), on occasions where they may choose to share their experiences, and where the DSN gets an opportunity to listen. During these short episodes, the DSNs and persons with T2D have a possibility to nurture a caring relation, beneficial for self-management. However, there is also a risk of the caring relation becoming tarnished due to high work demands, and not leading to empowerment.

### *Power relations*

Power relations were also identified in the interpersonal relationship between DSNs and patients (studies I, III, & IV). The results showed a complex professional role with high demands among DSNs (studies I & II) and ambivalence about working according to PCC values (study IV). The ambivalence was interpreted as a loss of authority and power. The DSNs perceived challenges and difficulties in fulfilling expectations, which made them ambiguous (study I). Power relations may imply a distance between DSNs and persons with T2D, since DSNs have a professional authority, while a patient is in a more or less dependent position, due to their illness, and thereby equality can be difficult to achieve (cf. Buber 1994). In a nursing context the word power is commonly negatively loaded, associated with hierarchy and authoritative leadership, restricting peoples' freedom of action (Kuokkanen & Leino-Kilpi 2000).

Power has been described as controlling, influencing, or dominating something or someone. Within nursing, there has been some criticism that power often has been discussed as oppressive, leading to reluctance among nurses to use power in practice, education, and research (Thorne & Henderson 1999). Manojlovich (2007) accentuated that power, on the other hand, concerns the ability to get things done, to mobilise resources, to get and use whatever a person needs to reach attempted goals. Different types of power have been described, such as legal, coercive, normative, and expert power. In nursing, expert power has been defined as an ability to influence others through possession of knowledge or skills that are useful to others for achieving health (Manojlovich 2007). This is also in line with Benner (2001), who stated that nurses' use of power includes caring practices that empower patients' own abilities.

DSNs need power not only to influence patients in a positive healthy direction, but also to influence physicians, other co-workers, managers, and their working situation (Manojlovich 2007). Powerless nurses have been described as less satisfied with their jobs (Manojlovich & Laschinger 2002). Manojlovich et al. (2007) have discussed powerlessness, as described by Freire (1970), as an individual assuming the role of an object acted upon by the environment, and not a subject acting in and on the environment. The DSN's exercise of power over persons with T2D can be interpreted as an attempt to emphasise professional authority and thereby also to distance oneself from the patients. The DSNs also used their power to influence and to put pressure on patients to improve self-management (studies I, III, & IV).

Since power in the encounter can be both oppressive (exercising power over) and progressive (facilitating empowerment), it can be of value for DSNs to accept that during a consultation there will probably be several

shifts in power positions (cf. Aléx & Hammarström 2008), something that was observed in study III. For DSNs it can be challenging when patients question their knowledge. However, the goal for the consultations should be that patients become empowered and take more and more control of their illness and self-management. The DSNs, on the other hand, described themselves as being quite lonely and having a large responsibility, and at the same time being subordinated to the GPs (study I). This is in line with Paynton (2009) who found that nurses' formal power – that is, power they have due to their position – was undermined by their subordination and by constraints in healthcare, while they used their informal power – that is, power they get by seeing the patients continually – to serve and advocate for patients' care.

Delivery of high quality diabetes care to patients is a complex activity and requires that professionals collaborate with one another (Reeves *et al.* 2013). Also, for DSNs' professional role development, it has been reported (Llahana & Hamric 2011), that support, good communication, recognition, and positive feedback from co-workers are required. Interpersonal collaboration between DSNs and GPs might need a further focus in the care. In primary healthcare, when investigating professionals' attitudes towards collaboration (Hansson *et al.* 2010), the authors found that nurses had more positive attitudes towards teamwork than GPs did. However, in a study by Fhärm *et al.* (2009), GPs expressed that diabetes care was dependent on DSNs rather than on themselves, and they supported them, pointing out that it was the DSNs who kept track of the patients. Instead of merely emphasizing better collaboration, the GPs might be interested in transferring more formal power to DSNs, such as in nurse-led diabetes clinics, which have been found to be beneficial for diabetes care (Arts *et al.* 2011, Juul *et al.* 2012).

The DSNs' communication included the use of medical language, and they stressed a medical perspective on diabetes and pronounced “truths and objectivity” (studies I & III). When the DSNs used an informative approach and set the agenda, the persons with T2D followed this agenda and began to ask questions only from the DSNs' point of view (study III). Using expert power to support people and supplying them with information, and simultaneously balancing the risks of oppressing patients with medical facts, is a fine line to walk. Advice on self-management activities may be neither achievable nor desired by the patients, particularly if it is given at a bad time. Expressions from professionals that could be apprehended as top-down or judgemental may include expressions such as “poorly controlled” and “non-compliant”. Use of such terms could lead to patients experiencing decreased confidence in professionals and to poorer communication about difficulties in self-management (Speight *et al.* 2012). When the DSNs tried to persuade patients to adapt to recommendations set by the healthcare service, resistance was observed among persons with T2D (study III). The patients

struggled to regain their authority and autonomy, which can be interpreted as a first step in an empowering process and in the patients' trajectory concerning learning to live with diabetes and developing expertise in self-management (Paterson & Thorne 2000, Thorne *et al.* 2000). Moser *et al.* (2010) found that patients perceived that their autonomy was supported by professionals' expressions of concern, and by interaction and collaboration between diabetes team members and by family members engaged in their self-management.

In patient education emphasising patient empowerment, the accustomed power positions among DSNs and patients are challenged. When patients increase their knowledge and take part in decision-making simultaneously with experiential learning, their commonly passive role is compromised (Cooper *et al.* 2003). Demonstrating resistance by missing appointments can be one way for persons with T2D to invoke their autonomy and thereby take back the power over their decisions concerning the illness and self-management activities in daily life. Opportunity to choose, freedom to decide, and activity in decision-making concerning one's own care and self-management increase patients' power and empowerment, an important argument to consider and a perspective from which to organise diabetes care (cf. Manojlovich 2007). However, empowerment can also be a disadvantage, if patients are not prepared or ready to take responsibility for self-management. Persons with diabetes have been described as experiencing a steep learning curve in self-management, surrounded by high levels of uncertainty, and thereby requiring on-going support that is modified according to their needs (Corcoran *et al.* 2012).

In situations where patients tried to regain power in the diabetes encounter (studies I & IV) by questioning the care and its quality, they demonstrated that they were ready for a power shift. However, patient empowerment was also seen as troublesome by the DSNs, who justified this response by reference to previous and on-going problematic situations in the healthcare service (studies I & III). DSNs seem to need support themselves to adapt to a power shift, so that they can adequately address and respond to patients' effort to take command over their illness, without simultaneously perceiving that their professional role is being questioned. It has been reported that such ambiguities among DSNs may relate to the fact that their function is in a developmental stage where their roles are being altered (van den Berg *et al.* 2008), but they may also be related to lack of time and education for professional development (Gosden *et al.* 2009).

There is an ongoing, politically driven paradigm shift involving a transition of power from professionals to patients in healthcare. In Sweden, a government report about patient power (SOU 2013: 2) resulted in two legislative proposals for future laws (SOU 2013:44). In the report, both patients' perspectives and their rights to power are emphasised. Patients should in

future have increased opportunities to influence, be informed about, and get involved in their care, and be able to choose healthcare alternatives according to availability and results. Shared responsibility and power (cf. Hughes *et al.* 2008) in the interpersonal relation between DSNs and persons with T2D can be a vital source for the development of quality diabetes care and for people to improve their self-management.

It is important that DSNs be aware that having the patient acting as an equal partner is an essential, powerful force, which can transform the image of the healthcare professions and improve the quality of care (cf. Hakesley-Brown & Malone 2007). According to Buber (1994), equality is essential in the interpersonal relationship. By this, Buber means that equality is something that one should strive for, even in relationships in which total equality is not possible, such as where one party is more needful than the other, who has a professional role to carry out, as in the case of DSNs and persons with T2D. One way to make the relationship more equal is to work according to person-centred values. From my point of view, a person-centred relation is an opportunity to strengthen patient empowerment in diabetes care.

### *A person-centred relation*

Several aspects of person-centred care (PCC) were identified in three of the studies (I, III, & IV). PCC was found to be both desirable and challenging, implying an altered professional role. PCC includes important aspects focusing on the relationship, good communication, shared responsibility, respect for people's needs, values, preferences, and priorities (Ekman *et al.* 2011, Hughes *et al.* 2008, Leplege *et al.* 2007, McCormack *et al.* 2010, Morgan & Yoder 2012, Slater 2006).

Through practising person-centred care in the intervention, the DSNs became more aware of the importance of seeing the person behind the illness, by listening to patients' points of view about the illness, and by engaging with them and discussing their practical and emotional problems as well as the disease severity (studies III & IV). The DSNs perceived high demands (study II) and expressed that they were expected to please everyone – colleagues, GPs, and patients – which was seen as a demanding challenge that caused them difficulties in engaging and being present and person-centred all the time (study I). On the other hand, they were aware of the benefits of PCC, such as an enriched relationship and shared responsibilities in care (study IV). An important part of a person-centred relation is that patients are invited by the DSNs to participate in the decision-making concerning their care, which is associated with better understanding and practice of self-management (Quinn *et al.* 2011). It has been reported that among persons with T2D who had participated in a group-based self-management pro-

gramme (Rise *et al.* 2013), it was important to gain knowledge about consequences and complications, taking responsibility for themselves, renewing habits, and also being supported and confirmed by others when making and maintaining lifestyle changes (Rise *et al.* 2013).

According to Buber (1994), confirmation is an essential part of a relationship. To be confirmed with respect to both abilities and shortcomings is essential in a person-centred relation. The interaction between the DSNs and persons with T2D during group sessions in general (study III) was interpreted as person-centred, however, in different degrees. During periods when the relation was person-centred, both parties confirmed each other and became empowered. Based on Buber (1994), such interaction reflects mutuality and equality. When the relation was less person-centred (study III), the parties at least met each other from different perspectives, consistent with what Buber (1994) described as acceptance. However, when both parties struggled for authority, the relation was interpreted as not, or to only a small extent, person-centred, and where aspects mentioned as important in an authentic relation, such as mutuality, equality, and confirmation, did not occur (cf. Buber 1994).

The DSNs were somewhat ambivalent towards PCC. Through practising it, they took on a more listening position and gave less information, which meant altering the accustomed professional role (study IV) as an expert, a fosterer, a leader, an executive, and a role model (study I). DSNs' education and work includes tasks that emanate from different perspectives on health, such as biomedical, public health, and life-world perspectives. These perspectives complement each other to ensure high quality diabetes care, but they may also collide. While treating patients from a public health perspective, where providing information about risks from a group perspective on treatment is common (cf. Wolf 2012), professionals may distance themselves from the experiences of persons with T2D, and this may counteract a person-centred relation. A difficulty is that general treatment goals, such as active glucose lowering, are not beneficial for all persons (Currie *et al.* 2010, Inzucchi *et al.* 2012). Furthermore, the care DSNs provide to persons with T2D is recommended based on various international and national guidelines with a higher emphasis on biomedical issues and tests parameters than on the person behind the disease, which might also be an obstacle for a person-centred relation (cf. Hörnsten 2004, Jutterström *et al.* 2012). An informative approach in diabetes care has been reported to be unsatisfying for patients, while a more reflective approach including open-ended questions could help patients to reflect upon their situations, creating new understandings (Holmström *et al.* 2004).

The DSNs perceived high quantitative demands (study II) and expressed that they lacked time to focus on each person's needs (studies I & IV). Lack of time has frequently been mentioned as a reason for shortcom-

ings in care and as a hindrance to PCC (Jansink *et al.* 2010, West *et al.* 2005), and might imply distance from patients. I mean that time is important, but not crucial. Attitudes and the ability to approach and relate to others are also vital for person-centred care. Nurses cannot address all persons the same way, since different people perceive and process events differently. Practising PCC in diabetes care means that DSNs need to distinguish and modify the care, based on people's abilities and various conditions. Ekman *et al.* (2012) stated that it is important for professionals to be sensitive, and that by listening to peoples' life stories, the time required for optimal care can be reduced.

The DSNs need to be aware of the differences in how they position the "I" of themselves in the encounter with persons with T2D. According to Buber (1994, 2011), there is a distinction within the "I", which means that one looks upon one's subject either as a person or as an individual. As a *person*, the "I" is real and belongs to the reality; the person says, "I am." The DSN as a *person* apprehends herself; catching her inner values and perceptions without any preconceived ideas. If the DSN, on the other hand, apprehends herself as an *individual*, she defines herself by what is hers, such as being a woman, being Swedish, being a DSN, and so on. An individual is not a part of the reality, since individuals frame themselves and say, "As this I am" (Buber 1994). If the "I" has more of an *individual* characteristic, the DSN frames herself towards patients' differences and tries to control as much as possible. If diabetes care is connected to Buber's philosophy, it is preferable to adopt the person-centred concept, instead of the patient-centred concept, since it accentuates and demands that professionals highlight the "I and You" relation.

### *A relation with proximity and distance*

An example of proximity in the results of the thesis was the DSNs' descriptions of how they engaged in the patients' care (study I). Support from colleagues and an empowering leadership were also important to them, interpreted as a need of proximity to other professionals and as a necessity for their perceptions of role clarity (study II). A close relation between the DSNs and the persons with T2D was also observed in group sessions in sections of the interaction that were characterised by empowerment (study III). The DSNs further described a close and enriched relationship with persons with T2D as a result of practising person-centred care during the intervention (study IV). One example of distance was the DSNs' striving to hold on to a powerful position as an expert, a fosterer, a leader, an executive, and a role model (study I). The DSNs also scored high demands in their work, which may lead to a distance from patients and others (study II). Distance was also

observed in the interaction when discussing patients' self-management, which ended up in a struggle for authority (study III). Lastly, distance from persons with T2D was identified when the DSNs were resistant to changing accustomed routines and referred to lack of time to prioritise engagement in each person's life circumstances (study IV).

According to Buber, we construct ourselves in the interpersonal act, and this construction depends on how we relate to and distance others and ourselves in the relation, where something new and durable may occur (Buber 1994, 1997). Even if distance may be interpreted as something that aggravates the relation, Buber also described distance as being connected to a relation. According to Buber, everything is twofold: if there is good, there is bad; if there is light, there is darkness; as there is I, there is you; and with proximity, there is distance. Distance from one's preconceptions is, according to Buber, a necessity to see each other's independence, uniqueness, and need for privacy, without superimposing a dream image upon the other or oneself (Buber 1997). Buber means that it is possible to choose how one relates to and confirms others, depending on how one succeeds in relating to and distancing oneself from others (Buber 1997). Distance can therefore enable DSNs to see the unique person in each patient. In addition, a DSN might be in need of distance from herself, to be able to reflect about her own part in the relation with persons with T2D.

## **Methodological considerations**

### *Design*

The choice of a particular design and method for data collection and analysis depends on the research question and/or theories adopted (Streubert & Carpenter 2010). By combining qualitative and quantitative methods, findings in a specific area can be broadened (Malterud 2001). I have chosen qualitative research methods to a larger extent, since I wanted to capture DSNs' perceptions, thoughts, and descriptions of their professional role and their actions when practising person-centred care (studies I, III, & IV).

A qualitative design was therefore purposeful in studies I, III, and IV, while a quantitative design was used to capture psychosocial work aspects in a group of DSNs (study II).

### *Sample and participants*

In all studies (I–IV) a purposeful sample was made, based on availability, voluntary participation, and the DSNs' particular knowledge about the issues under study, and the fact of their working as DSNs in the investigated regions. Since a purposeful sample does not truly represent a population, it is difficult to generalise the result to a larger population (Polit & Beck 2013). Therefore, transferability (of findings to, for example, other contexts and populations) has been suggested by Graneheim and Lundman (2004) to be more appropriate in qualitative research. I suggest that the result can be transferable to other contexts of caring for patients with chronic illnesses. The sample size in Study II was relatively small. One reason for this was that there are relatively few nurses working as DSNs in the county. However, the sample consisted of 31 of approximately 45 DSNs in the county. The response rate was 69% with internal missing values below 0.8%, which was considered sufficient to do the analyses. Furthermore, this group of DSNs was compared with a reference group. Since the reference group only had data on mean level, non-parametric tests could not be carried out, and therefore one-sample *t*-tests were conducted. However, when drawing conclusions from study II, caution should be taken, since the sample is quite small making it difficult to generalise the results.

One important consideration for trustworthiness of qualitative research is the richness of the data. The number of participants in the studies of this thesis has been considered sufficient. In study I, 29 DSNs participated. In study III, 10 DSNs and 44 patients participated, and finally, in study IV, 10 DSNs participated. The participants in studies III and IV were all the DSNs who participated in the intervention. In study III also, 44 patients (70%) participated in the group sessions that were observed, which also is considered sufficient. Polit and Beck (2013) have recommended conducting 10–15 interviews to have the research question answered. In the studies in this thesis, only a few men participated, in total two men in study I and one in study II. The reason was that only a few men work as DSNs in the county.

### *Data collection*

Individual and focus groups interviews were used to explore DSNs' perceptions and experiences. Focus group interviews (studies I & IV) were chosen to capture the knowledge and experiences in a group of participants. One risk with focus group interviews is that they may mirror group thinking, and some participants' opinions may dominate. However, in the two focus group studies this was counteracted by moderation of the discussion and by encouraging those speaking less, thereby allowing everybody to contribute their

opinions and experiences (cf. Morgan & Bottorff 2010). Furthermore, the atmosphere was friendly, and rich data about the issue of interest were collected. Individual interviews (study IV) were chosen to get more in-depth data about the issue under study to complete data gathered in the focus group interviews.

Observations were chosen to explore the interaction between DSNs and persons with T2D during group sessions. During observations there was a risk that participants would feel uncomfortable being observed. To counteract this, the fifth session was selected for observation, where the participants had become more acquainted with each other by then. Participatory observation is an appropriate method of collecting data in clinical settings when not only the verbal and non-verbal communication, and the activities, behaviours, and events but also environmental aspects are under study (Polit & Beck 2013). During the observations, I was aware that my presence could be perceived by the participants as controlling. I tried to prevent this impression by repeating information about the purpose of the study at the beginning of the observations, emphasising that I had no answers or opinions regarding the interactions between them. Furthermore, I was neutrally dressed and took a position on the side to reduce the risk of influencing the interaction (cf. Hammersley & Atkinson 2007). There is always a risk of the observer influencing and being influenced by the interaction and thus biasing the findings. Through reflection, I tried to guard against such bias (Polit & Beck 2013). After the observations, I listened through the audiotape recordings and made notes, while reflecting critically on my own reactions and personal values in order to address the credibility of the findings.

Questionnaires were chosen as a mean to collect data about psychosocial aspects of work. The use of questionnaires is advantageous for geographically dispersed samples, as in this case. Questionnaires also offer the possibility of a higher level of confidentiality, since the researcher and the participants do not have to meet. This can be crucial when data are obtained about certain behaviours and opinions, and might have been important in this study about psychosocial aspects of work. A disadvantage of questionnaires is that respondents may answer superficially, especially if the questionnaire takes a long time to complete, which this did. A common mistake could also be asking too many questions, something that should be avoided (Polit & Beck 2013). However, the motive for choosing this questionnaire was that it had been previously validated and tested for reliability (Dallner *et al.* 2000, Wännström *et al.* 2009). Another difficulty was encountered in analysing non-responders, a rate of about one third. There were no background data of eligible participants at baseline, except that they worked as primary healthcare nurses at a primary healthcare centre in the region. However, there were at the time for the study about 45 active DSNs working in the county council, of whom 31 reported having responsibility for a dia-

betes clinic. The geographical distribution and gender did not differ between responders and non-responders. Thus, the sample was quite representative for the total population of DSNs working in the county council (cf. Polit & Beck 2013).

### *Trustworthiness of analysis*

Experience concerning diabetes care can be seen as a strength or a limitation. I had limited experience, and thereby it was possible to be open minded concerning DSNs and their work. If I, as a researcher, have an open mind as to what I'm supposed to explore, without being accustomed to earlier traditions, I might be able to see the "otherness" in the situation, the new perspectives that goes beyond the horizon of what is already known (cf. Nyström & Dahlberg 2001). On the other hand, preconceptions and experiences might also enrich the data collection and analysis, since complex procedures and issues could be more easily understood. To determine the credibility of a qualitative analysis, the researchers can choose to present preliminary findings to the participants. The findings (study I) were presented to about one third of the participants, who found them to be trustworthy and to mirror their experiences. A text does not contain only *one* given meaning (Krippendorff 2004). The interpretations made in this thesis can therefore be seen as one set out of several possible interpretations.

The credibility of interpretations was determined from discussions with senior researchers in and outside the research group, and among graduate students in seminars (cf. Graneheim & Lundman 2004, Streubert & Carpenter 2010). In the qualitative studies included, two members of the research team coded parts of the material independently to be assured of its intersubjectivity. The analysis was also repeatedly discussed among authors to make sure that the interpretations were sustainable and therefore reliable. Qualitative research reports the method and analytic process thoroughly, and in the results, quotes was included to help the reader to create an understanding of and assess the trustworthiness of the analysis (Graneheim & Lundman 2004). Thus, it could be argued that the interpretations in this thesis are trustworthy for these data in this context.

## **Conclusions and clinical implications**

This thesis shows that proximity and distance are constantly present in the DSNs' diabetes care. DSNs have a desire to be close to persons with T2D, although they have several challenges to fulfil, which makes it difficult to uphold a relation with proximity; as a consequence, distance is also present.

The results of this thesis show that PCC also implies an altered professional role for DSNs that has to be addressed.

Practising PCC may strengthen DSNs in their professional role. By practising PCC, an interpersonal relationship between the DSNs and persons with T2D can be facilitated. Person-centred care addresses matters that are important for persons with T2D. By changing DSNs approach from an informative one to a person-centred approach that includes more listening, encouraging, and relating, they could better support persons with T2D to make well-informed decisions about self-management. It is also important to invite the persons with T2D into the diabetes team for reflective dialogues.

With support and training to implement PCC in their practice, the DSNs could become more confident in their altered professional role. It is vital that the DSNs be able to prioritise time for diabetes care and diabetes-related tasks within their professional role, to avoid becoming torn and fragmented between different tasks at their primary healthcare centre. Support of patients' self-management in groups is recommended in diabetes guidelines, and this thesis shows that it is possible and important to develop this activity. By becoming aware of the altered professional role and the challenges that might occur in the practice of PCC, the DSNs could more easily contribute to a shift of culture in diabetes care towards a more mutual, trustful, and respectful care, where each patient is seen as a unique person with T2D.

## **Future research**

Research among DSNs in a larger context might confirm the findings of this thesis. Further observational studies of the interaction between DSNs and persons with T2D would add more knowledge about the clinical encounter. Furthermore, through observations of DSNs' and GPs' interactions, and the diabetes team that surrounds the person with T2D, prevailing discourses in diabetes care could be explored. The person with T2D is part of a system where the family members have important roles in facilitating self-management. Research on the importance of family members and their participation in the diabetes care and the diabetes team is also an important focus for future research.

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**Department of Nursing**

Umeå University

SE-901 87 Umeå, Sweden

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