

UMEÅ UNIVERSITY MEDICAL DISSERTATIONS
New Series No 882 – ISSN 0346-6612

From the Department of Nursing and the Department of Public Health and
Clinical Medicine, Family medicine, Umeå University, Umeå, Sweden

Experiences of Diabetes Care – Patients' and Nurses' Perspectives

Åsa Hörnsten



Umeå 2004

Copyright 2004 by Åsa Hörnsten
ISBN 91-7305-619-7

Printed in Sweden by Solfjädern Offset AB
Umeå 2004

TABLE OF CONTENT

TABLE OF CONTENT	3
ABSTRACT	5
ORIGINAL PAPERS	6
ABBREVIATIONS	7
BACKGROUND	8
<i>Theoretical framework for the thesis</i>	8
The meaning of illness and disease	9
<i>Diabetes</i>	11
Diabetes type 2 and its treatment	12
<i>Living with chronic illness</i>	13
Personal understanding of illness	15
Living with diabetes	15
<i>Organization and goals of diabetes care in Sweden</i>	16
The role of the diabetes nurse in primary care	17
A model for diabetes care.....	17
<i>The patient-professional relationship and communication</i>	18
Contrasting patients' and professionals' perspectives on diabetes, and diabetes care	19
Outcome of interventions	20
RATIONALE FOR AND AIMS OF THE THESIS	21
METHODS	23
<i>Settings and participants</i>	23
Settings	23
Participants and sampling.....	23
<i>Intervention</i>	25
Intervention aimed at nurses	25
Intervention aimed at patients	25
Patient group sessions	26
<i>Data collection and analyses</i>	27
Interviews (Papers I–IV)	27
Questionnaires (Paper V)	27
Laboratory/Physical Measurements (Paper V)	29
<i>Data analysis</i>	29
Content analysis (Papers I–IV)	29
Statistical analyses (Paper V).....	32
<i>Methodological considerations</i>	33
FINDINGS	34

DISCUSSION	39
<i>Summary and clinical implications</i>	<i>43</i>
<i>Conclusion.....</i>	<i>46</i>
SUMMARY IN SWEDISH – SVENSK SAMMANFATTNING.....	47
ACKNOWLEDGEMENTS.....	49
REFERENCES	51
PAPERS I - V	

ABSTRACT

Background: In order to provide good diabetes care it is important for the health care professionals to share patients' personal understanding of living with diabetes, which differs from a professional understanding of the illness. Patients' beliefs about health, illness, control and cure are predictive of the outcome of lifestyle changes and pharmacological treatment. Narratives about illness could be used to elucidate what people believe to be central to their experience of an illness and its management. The overall aim of this thesis was to investigate experiences of diabetes and diabetes care among people with type 2 diabetes and district nurses responsible for diabetes care within primary health care.

Methods: Forty-four patients diagnosed with diabetes during the previous 2 years were interviewed about their personal understanding of illness and experiences of care. They also participated in an intervention study consisting of group sessions during 9 months. The intervention focused on the patients' understanding of living with diabetes and was directed at the patients and their nurses ($n = 5$). The outcome variables haemoglobin A_{1c} (HbA_{1c}), lipids, blood pressure (BP) and body mass index (BMI) as well as well-being, treatment satisfaction and diabetes symptoms of the intervention group were compared with those in a control group ($n = 60$). Another ten patients were interviewed about their views of their lives. Seventeen nurses in diabetes care were interviewed about their views of their work with patients. The narrative, thematic interviews and focus group interviews were analysed using qualitative content analysis.

Findings: Patients' personal understanding of illness included the categories "image of the disease"; "meaning of the diagnosis"; "integration of the illness"; "space for the illness"; "responsibility for care"; and "future prospects". Patients' narratives about their lives included views of knowledge, and capacity, motivation and courage, aspects important for effective self-management. Patients' views on clinical encounters in diabetes care, interpreted as satisfying or not, included the themes "being in agreement v. in disagreement about the goals"; "being autonomous and equal v. being forced into adaptation and submission"; "feeling worthy as a person v. feeling worthless"; "being attended to and feeling welcome v. being ignored"; and "feeling safe and confident v. feeling unsafe and lacking confidence". The results of the intervention study with group sessions showed improvements in metabolic balance and treatment satisfaction in the intervention group. At the 1-year follow-up the mean difference between groups in HbA_{1c} was 0.94% (95% confidence interval (CI) 0.58–1.29). Nurses' views of their work included the themes "Perspectives on illness and caring are not easily integrated into views of disease and its treatment"; "Nurses view their knowledge as more important than the patients' knowledge"; Nurses' conscience is challenged by some of their nursing decisions"; "The individuality of each patient is undermined when patients are regarded as a collective group"; and "Nurses are confirmed in their role of nurses by patients who assume a traditional patient role".

Conclusion: These results demonstrate that the understanding of illness and care differs between patients and nurses working in diabetes care; furthermore, that an intervention involving patients and their nurses based on patients' personal understanding of illness is effective with regard to metabolic control and treatment satisfaction. The cost of the intervention is moderate. Also, we believe that it is possible to clinically implement this intervention within the existing resources for primary health care.

Key words: diabetes type 2, haemoglobin A_{1c} (HbA_{1c}), primary health care, clinical encounters, group sessions, intervention, professional perspective, patient perspective, narratives, qualitative content analysis

ORIGINAL PAPERS

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

- I. Hörnsten Å, Sandström H, Lundman B. Personal understanding of illness among people with type 2-diabetes. *Journal of Advanced Nursing*, accepted November 2003.
- II. Hörnsten Å, Norberg A, Lundman B. (2002) Psychosocial maturity among people with type 2-diabetes. *Journal of Clinical Nursing*, 11, 777-784.
- III. Hörnsten Å, Kihl Selstam E, Sandström H, Lundman B. Patient satisfaction with encounters in diabetes care as narrated by people with type 2 diabetes in Sweden. Submitted.
- IV. Hörnsten Å, Almberg A, Sandström H, Lundman B. Nurses' views of their work with patients in diabetes care. Submitted.
- V. Hörnsten Å, Lundman B, Stenlund H, Sandström H. Metabolic improvement after intervention focusing on personal understanding of diabetes. Submitted.

ABBREVIATIONS

DCCT	Diabetes Control and Complications Trial
UKPDS	United Kingdom Prospective Diabetes Study
HCC	Health care centre (in primary care)
HCP	Health care professional (nurses, doctors or other members of the diabetes team)
SD	Standard Deviation
CI	Confidence Interval
α	Alpha
HbA _{1c}	Hemoglobin A _{1c}
Chol	Total cholesterol
HDL	High Density Lipoprotein
LDL	Low Density Lipoprotein
BMI	Body Mass Index
BP	Blood Pressure

INTRODUCTION

My interest in this research area is based upon own experiences of health care, mainly obtained as a nurse in hospital and primary health care. I have been a registered nurse since 1985 and initially worked in orthopaedics, neuro-surgery and internal medicine wards. Later I specialized in anaesthetic care and worked as an anaesthetic nurse. In 1993 I decided to specialize as a district nurse and later, in diabetes care. I immediately felt “at home” in my work as a district nurse and particularly in home care. Home care, which I consider to be at the heart of the district nurse’s work, differs greatly from hospital care since I feel that in the hospital the medical professional perspective still prevails and dominates. I found out that the best way, and often the only way, to succeed in establishing a long-standing relation with a patient, which is satisfying to both parties, is to remove the “professional” (i.e. distancing) role and try to become a partner with the patient. My interpretation is that I became interested in the patient perspective by being “close to the patient’s world”. This, then, was the perspective for my present research. In this thesis I mostly highlight the patient’s perspective as a powerful and necessary factor that has to be a basis of any nursing intervention. In 1996 when I started my Masters education I became involved in a research project named “Testing a model for nursing among people with diabetes type 2”, which also was the starting point for the research performed for my PhD.

BACKGROUND

The following chapter is a presentation of the theoretical framework adopted for the thesis. It also aims to present research about diabetes, about living with diabetes and about the organization of diabetes care in theory and practice including interventions and communication between patients and professionals.

Theoretical framework for the thesis

The theories on illness and disease as well as the underlying philosophies on concepts that form the theoretical framework for the thesis are described below. The illness perspective is based on a life-world perspective, an insider perspective on illness, which means that I have tried to enter the patient’s life-world in interpreting data. The disease perspective is based on the literature and also, on nurses’ professional life-worlds as well as on my own experiences of care – in other words, on an outsider’s perspective on patients’ illness experiences.

The meaning of illness and disease

The difference in meaning of the concepts “illness” and “disease” is problematic, particularly in Sweden as the Swedish language lacks the concept of or word corresponding to “illness” and therefore the word “disease” is used for both “illness” and “disease”. One of the most influential theoretical works on illness experiences is the anthropologist Kleinman’s (1988) monograph “The illness narratives”. Many other researchers have contended that illness experiences are fundamentally different from the disease perspective (see, e.g., Fabrega, 1974; Eisenberg, 1977; Jennings, 1986; Conrad, 1987; Bury, 1991; Toombs, 1993; Atkinson, 1995; Conrad & Bury, 1997). The disease perspective is based upon “the medical model”, which is concerned with viewing the non-diseased body as “normal” and disease as a deviation from the patient’s natural state or from statistical norms, independent of particular experiences or circumstances (Lawrence, 1994). Kleinman (1988) defines illness as a social experience that is a dynamic process in which sick persons, their family and their social network perceive, live with and respond to symptoms and disability. Toombs (1995) argues that the experience of illness is subjective, has to do with losing bodily functions or not functioning as well as before and is based on how the disease is understood in daily life. According to Conrad (1987), “illness” is a critical aspect of being ill and includes what we are experiencing, what we are doing and what we are feeling while we are ill. The experience of illness is best studied inductively by interviews, with questions such as, “What felt wrong?”, “Why did you seek care?”, “How can you manage this situation?” and “How is your life affected by the illness?” (Conrad, 1987) According to Bury (1991), the term “illness” refers to the experience of, that is, the feelings and sensations during and attitudes towards, a physical and/or psychological and social disturbance or suffering. Illness is innately human. It includes recognizing that bodily processes are malfunctioning and usually, taking steps to rectify the situation, such as seeking treatment.

Disease, on the other hand, is not limited to humans. For instance, we talk about a “diseased” apple. The term “disease” is technically defined as a malfunction or deviation from the biological norm, which is scientifically diagnosed. This definition does not imply that disease is an objective state, since it is categorised and influenced by social, historical and political contexts (Lupton, 1994, p 93). The physician Eisenberg in his influential study of 1977 distinguishes between disease and illness stating that patients suffer “illnesses” while physicians diagnose and treat “diseases”. He further states that whereas disease is an abnormality in the structure and function of the body’s organs and systems, illness is an experience of devalued changes in states of being and social functions. Cassel (1976) in his study of interactions between doctors and

patients focused upon the ways in which diseases and body parts are referred to in common speech usage. He found that diseases and symptoms are frequently described using impersonal pronouns and terms such as “it” or “the disease” rather than personal pronouns such as “my” or “I”. This usage may signify that patients do not always view their disease as part of themselves, but as entities that exist apart from themselves.

Likewise, the philosopher Kay Toombs (1993, p 1) argues that illness and disease are experienced from different perspectives, namely from the “separate worlds of [the] physician and [the] patient”. The patient’s and health professional’s experiences are separated in five dimensions, the first being the *focus*. Whereas the physician to make a diagnosis focuses on processes, signs and symptoms that resemble typical cases of diseases the patient focuses on effects on daily life and function. *Attitudes* is the second dimension in which the two parties differ. While the physician has a naturalistic attitude leading to a scientific abstraction the patient represents the natural attitude, in terms of which life is taken for granted and actions are subjective and pragmatic. The third dimension is *time*. The physician uses an objective time scale to measure and define the patient’s state. The patient’s experience of time, especially during suffering, is not objective. The fourth dimension has to do with *relevance*, with the process of the disease and the clinical data being important in the scientific work of the professional. By contrast, the patient views pragmatic motives and effects of illness as more relevant in his or her daily life. The fifth and last dimension of the different life-worlds of the physician and patient is the striving for a *common communication*, which does not imply that the language used is a common basis. The physician interprets the patient’s experiences on the basis of typical cases while the patient describes the problems as unique events with existential elements. The words that are used may illustrate the different perspectives. The word “diagnosis”, which is frequently used among physicians, corresponds to the word “exploring” used by the patient, containing a confirmation that the experiences one has had are appropriate. Giving “treatment” corresponds with getting a “cure”, or returning to the life one had before. “Prognosis” corresponds to “prediction”, meaning to know what personally is going to happen to oneself in the future. These differences are not merely based on different levels of knowledge, but particularly on a difference between lived experience and the *scientific conception or paradigm* (Toombs, 1995). Patients’ and professionals’ perspectives of illness and disease adapted to diabetes and diabetes care is the framework for the thesis.

Diabetes

In June 1997 an international group in collaboration with experts from the American Diabetes Association (ADA) and the World Health Organisation (WHO) released a report with new recommendations for the classification and diagnosis of diabetes mellitus. The new classification identifies four types of diabetes mellitus: type 1, type 2, “other specific types” and gestational diabetes (Expert Committee, 1997). In the following, “diabetes mellitus” will be referred to as, simply, “diabetes”.

Diabetes type 1 is characterised by beta cell destruction caused by an auto-immune process, usually leading to absolute insulin deficiency. Most of these patients have the “immune-mediated form” of diabetes type 1 with islet cell antibodies. The onset of this type of diabetes is usually acute, with signs developing over a period of a few days to weeks. Over 95% of persons with diabetes type 1 develop the disease before the age of 25, with an equal incidence in both sexes and an increased prevalence in the white population. (National Diabetes Data Group, 1995; Expert Committee, 1997).

Diabetes type 2 is a complex metabolic disorder characterised by hyperglycaemia associated with a relative deficiency of insulin secretion and insulin resistance in target tissues. This is the most common form of diabetes and is highly associated with older age, obesity and lack of exercise. It is more common in women, especially women with a history of gestational diabetes, and in blacks, Hispanics and Native Americans. Insulin resistance and hyperinsulinemia gradually lead to impaired glucose tolerance. Diabetes, type 2 is recognised as one manifestation of the “metabolic syndrome”, a condition characterised by insulin resistance, obesity, hypertension and dyslipidemia. The etiology of diabetes type 2 is multifactorial with a considerable genetic component but the disease also is life style and environmentally related. (National Diabetes Data Group, 1995; Expert Committee, 1997).

Types of diabetes of various known aetiologies have been grouped together under the classification “other specific types”. This group includes genetic defects of beta cell function, such as maturity-onset diabetes in youth (MODY), or defects of insulin action; diseases of the exocrine pancreas, such as pancreatitis or cystic fibrosis; dysfunction associated with other endocrinopathies (e.g. acromegaly); and pancreatic dysfunction caused by drugs, chemicals or infection (National Diabetes Data Group, 1995; Expert Committee, 1997).

Previously undiagnosed asymptomatic diabetes type 2 (or type 1) that is discovered during pregnancy is classified as “gestational diabetes”. In most women the hyperglycaemia resolves after delivery but places them at increased risk of developing diabetes type 2 later in life. Among Swedish women diagnosed with gestational diabetes during pregnancy about one-third in a more or less linear fashion developed diabetes type 2 over a 15-year period (Linné et al, 2002).

Diabetes type 2 and its treatment

In Sweden, a country of about 8.9 million inhabitants, diabetes has been reported to be prevalent in about 3.3–4.3% of the population (Falkenberg, 1990; Andersson, 1994; Lundman & Engström, 1998) and about 90% of people with diabetes are estimated to have diabetes type 2 (Agardh et al, 2002). Despite its high prevalence it is a highly under-diagnosed condition as it initially is asymptomatic. Swedish studies have estimated the proportion of undiagnosed people with diabetes to be about one out of three (Socialstyrelsen, 2001; Agardh et al, 2002).

Diabetes type 2 causes abnormal carbohydrate, lipid and protein metabolism associated with insulin resistance and relative insulin deficiency (Expert Committee, 1997). The progression of diabetes is caused by numerous metabolic events that occur over a period of years. By controlling these metabolic disturbances, the progression of the disease may be slowed. All treatment strategies emphasize risk reduction of complications, based on non-pharmacological treatment focusing on smoking cessation, diet modification, weight control and regular exercise (Agardh et al, 2002). Pharmacological treatment with oral agents and/or insulin is based on the patients’ characteristics and the various metabolic abnormalities they show, including hypertension. (WHO 2002).

Results of a large longitudinal study of patients with diabetes type 2, the United Kingdom Prospective Diabetes Study (UKPDS) designed as a randomised controlled study comparing intensively treated with conventionally treated patients, suggest that any reduction of haemoglobin A_{1c} (HbA_{1c}) levels among people with diabetes type 2 is likely to reduce the risk for complications, with the lowest risk being in those with HbA_{1c} values in the normal range (Stratton et al, 2000). The UKPDS conclusively demonstrated that intensive treatment reduces the risk for overall microvascular complications by 25% (Kothari et al, 2002). Furthermore, the UKPDS showed that diabetes type 2 is a progressive disease and that mean HbA_{1c} levels increased by 1% in 4 years among the participants (UKPDS, 1998). The study also showed that each 10 mmHg

decrease in mean systolic blood pressure (BP) was associated with reductions in risk of 12% for any complication related to diabetes, 15% for death related to diabetes, 11% for myocardial infarction and 13% for microvascular complications (Adler et al, 2000). Complications are reported to decrease well-being and quality of life, but intensive blood glucose control does not (UKPDS, 1999; Hahl et al, 2002). Intensive blood glucose control has also been shown to significantly increase treatment costs and to substantially reduce the cost of complications and increase the time free from complications (Gray et al, 2000).

Living with chronic illness

Parsons (1951) described a typical approach to chronic disabling illness, which says that chronic illness is regarded as an undesirable state hedged in by restrictions and limitations. Furthermore, Frank (1997, p 132) concludes that the Parsonian paradigm transforms the ill person into the patient who becomes a “suspicious character”. The physician, says Frank, is expected to treat the patient “without colluding in the patient’s withdrawal into sickness”. Frank (1997), Freidson (1970), Zola (1973) and Mishler (1984) among others reject the Parsonian view and question professional dominance and instead promote viewing the patient as central to the process of illness. Nowadays many researchers argue in the same way (Kleinman, 1988; Bury, 1991; Charmaz, 1991; Morse, 1997; Toombs, 1995) and seek to move the emphasis from the passive patient to a person who takes action. The physician rather than regulating and limiting illness is seen as more supportive in the patient’s acceptance of illness (Anderson & Funnell, 2000; Frank, 1997; Paterson, 2001a). Frank (1997, p 136) suggests that attention should be shifted from the undesirability of illness to “being successfully ill”, in which people creatively and meaningfully live with illnesses. Charmaz (1991, p 7) proposes that chronic illness may “rip apart taken for granted daily routines”, forcing people to relate especially to time in new ways. According to Charmaz, “chronic illness often chrysalises vital lessons about living”.

Many researchers have described living with chronic illness, including Michael (1996) who reports how patients with chronic illnesses have integrated these into their lives. Rush deals with themes such as *being confronted with losses*, which implies not functioning as well as before, and being confronted with changed affinity with others; as well as a *fluctuating feeling*, which term describes a mix of frustration, guilt, anger and fear; and *changed routines* which lead to dilemmas about identity conflicts related to meeting the demands. Finally, *control over an altered life situation*, which includes seeking support, learning about the disease, fighting against or striving to cope with the demands

and making the illness meaningful, helps people to integrate the disease (Michael, 1996).

Paterson (2001b) in a meta-synthesis of 292 qualitative research reports pertaining to chronic physical illness has developed the “shifting perspectives model of chronic illness” which describes a dialectical, constantly shifting perspective in which either illness or wellness is in the foreground. It also describes the individuation of the chronic illness experience, and the reasons why people vary in their attention to symptoms, and directs practitioners to support persons with either perspective. Quite contrary to previous researchers who have described living with chronic illness as a phased process in which the person follows a predictable trajectory with an end-goal, Paterson has found that living with chronic illness is an ongoing, continually *shifting* process in which people experience a complex dialectic between themselves and their “world”, enabling them to make sense of their experience. An *illness-in-the-foreground perspective* is, according to Paterson (2001b), often adopted by newly diagnosed people who are overwhelmed by the disease, but can also be adopted in other situations including some threat to control since this perspective has a protective, maintenance, or utilitarian function. This perspective focuses on the sickness as well as suffering, loss and burden. Benefits of adopting an illness-in-the-foreground perspective may include that it forces a person to attend to the illness and it helps the person learn about the disease, reflect on it and come to terms with it. By contrast, a *wellness-in-the-foreground perspective* focuses on the emotional, spiritual and social aspects of life rather than on the diseased body, which is objectified and placed at a distance. Benefits of adopting a wellness-in-the-foreground perspective may include being allowed to mediate the effects of the disease, and shifting from the position of a victim to that of creator of circumstances (Paterson, 2001b).

Hagger and Orbell (2003) have performed a meta-analysis of empirical studies adopting Leventhal, Meyer and Nerenz’s (1980) Commons Sense Model (CSM) of illness representation. They found a relationship between illness cognitions, coping and outcome, e.g. perceptions of strong illness correlated significantly with use of coping strategies of avoidance and emotion expressions. Perceived controllability of the illness was associated with cognitive reappraisal, expressing emotions and problem-focused coping strategies. Illness perceived as highly symptomatic, with a chronic time line and serious consequences, is correlated with avoidance and expressing emotional coping strategies. Finally, the perception that illness is curable/controllable is positively related to psychological well-being, social functioning and vitality, but negatively related to psychological distress and the disease state (Hagger & Orbell, 2003).

Personal understanding of illness

Explanatory models and personal models are concerned with identifying how people understand their illness, in other words, identifying the components that people with diseases believe to be central to their experience of an illness and its management. The concept of “explanatory models” is used for understanding illness from both a professional and a lay point of view, while “illness representation” exclusively focuses on the patient’s beliefs about illness (McSweeney et al, 1997). Personal models include emotional responses (e.g. worries, fear) to the disease and treatment, a component that is lacking in many other reports on beliefs about health and illness (Poss & Jezewski, 2002). In this thesis I will use the concept “personal understanding of illness” to refer to the complex intertwining of thoughts, feelings, explanations and understanding involved in the illness experience. The following components are frequently reported to be important in personal explanatory models: identity/label, cause, consequences, time line, and control/cure (Kleinman, 1988; Lau et al, 1983). Among adult people with diabetes, beliefs about control and cure have been found to be predictive of dietary and exercise management (Hampson et al, 1990; 1995).

Living with diabetes

A great deal of the diabetes literature argues for resourceful patients who take charge, are innovative, have the inner strength and resources to meet challenges (Anderson et al, 1991; Paterson & Sloan, 1994; Ellison & Rayman, 1998) and progress through challenging phases with diabetes in their life (Hernandez, 1995).

Management of diabetes type 2 requires lifestyle changes including dietary adjustments, exercising regularly, adherence to medication and blood sugar testing as well as going for medical check-ups, which some patients experience as demanding. At the same time, people diagnosed with diabetes type 2 are advised to live as normally as possible and maintain their well-being. Paterson et al (1998) in a meta-analysis of 47 qualitative studies demonstrate that in order to adapt to and manage their illness, patients with diabetes have to balance between demands that are sometimes contradictory. These demands include controlling and being controlled by the diabetes; exercising control by oneself and being controlled by others; accepting oneself as a person with diabetes and yet having a positive self-image; adapting to the demands of the diabetes and not being ill; developing patterns and at the same time adapting to changes; getting basic and meaningful knowledge; need for good metabolic control and need for naturally relations to family and friends and finally Paterson et al mention in the relation with the caregiver, finding a balance between daring to say what one thinks and

at the same time not being seen as a troublesome patient. All studies referred to in Paterson et al's meta-analysis point to the necessity in a successful management of diabetes of taking a conscious decision about taking control by oneself over the disease and treatment (Paterson et al, 1998).

Francioni & Silva (2002) interviewed people with diabetes in order to understand the process of accepting to live with diabetes. They highlight four categories, namely: "to find out was terrible"; "it is hard to live with it"; "but you have to accept it"; and "it is possible to have a good life, even with diabetes". Paterson et al (1999) describe how patients with diabetes type 1 develop a transformed self, differentiated from the body and the illness. The transformation is, according to the authors, both an outcome of tackling an illness-related challenge and a strategy to mediate the impact of illness. Nyhlin et al (1987) interviewed well-adapted patients with diabetes type 1 without any complications despite a long duration of the disease, and report that their experiences of dealing with diabetes can be divided into the following categories: "up to oneself"; "walking a fine line"; "the days are numbered"; "not ill but having a disease"; "being dependently independent".

Koch et al (1999) in a study among women with diabetes type 2 report that women experience diabetes negatively, as bringing only restrictions. They often have to cope with depression and fatigue, with social consequences such as being set apart, and find living with diabetes stressful because it demands that they are constantly vigilant. The interviewed women talked about a poor quality of the doctor-patient relationship, coercion used by the doctors to ensure adherence to biomedical treatment regimens and also, failure on the part of the doctor to perceive problems from the patient's perspective as well as an attempt to invalidate and disregard the patient's experiences in relation to management of her diabetes (Koch et al, 1999).

Organization and goals of diabetes care in Sweden

In Sweden people with diabetes type 1 most often are managed by diabetes specialists and diabetes teams at hospital clinics, while people with diabetes type 2 usually fall under primary health care and the care of their general practitioner and district/diabetes nurse, often organized into a diabetes team together with a podiatrist and welfare officer. Swedish diabetes care is organised according to the national guidelines laid down by the Swedish National Board of Health and Welfare (Socialstyrelsen, 1999) inspired by the St Vincent Declaration based on reports from the diabetes experts committee (WHO & IDF, 1995). The guidelines give short-term goals, which include avoiding hypoglycaemia, normalising HbA_{1c} and blood lipid levels and BP, reducing body weight and at

the same time, sustaining a high degree of quality of life for the patients. Intermediate goals include preventing the emergence of retinopathy and neuropathy. Finally, long-term goals include reducing blindness, terminal kidney disease, amputations and cardiovascular morbidity.

The role of the diabetes nurse in primary care

In its guidelines the Swedish National Board of Health and Welfare declares that a prerequisite to reaching the stated goals is competent medical treatment and also, sufficient self-care mediated by well-educated health care personnel. The patient's education in self-care is central to diabetes care and the diabetes nurse is expected to play an important role in this work of supporting the patient in acquiring knowledge and confidence in order to reach the goals for metabolic control declared in the national guidelines (Socialstyrelsen, 1999). District nurses educated in diabetes care and working in primary health care are often responsible for providing diabetes care quite independently of the general practitioner, for instance when making adjustments to tablets and insulin doses. This kind of organisation has been promoted in several policy documents and research reports for the high quality of the care it provides (Alberti & Gries, 1988; Carlsson & Rosenqvist, 1991; Weinberger et al, 1995; Keen, 1996; Ovhed et al, 2000).

A model for diabetes care

My project is based on a model for diabetes care by Lundman (1990). Within my research I entered deeply into some parts of Lundman's model for care, involving the patients' maturity, their understanding of illness and care and also, diabetes nurses' views of their work with patients in diabetes care. The aim, according to Lundman, of creating the model was to bring more clarity to the complex relationship between the patient's perspective on illness and care on the one hand and the HCP's perspective on the other. Lundman's model points to important personal characteristics and factors that influence the outcome of care and the interaction between the patient and the HCP. For example, the patient's and the HCP's maturity, age and gender, global orientation, previous experiences of care, and social support are considered as important aspects that affect the outcome of care. Within the present care situation, their coping strategies, habits and priorities, knowledge, and experiences of the disease and illness affect both the outcome of care and the interaction. If the interaction is meaningful and effective, it will affect the outcome by means of improved metabolic control, fewer complications and increased well-being (Lundman, 1990).

The patient-professional relationship and communication

In the literature a great deal of research has been done on communication between the patient and the health professional and in particular the doctor-patient relationship has been studied although there are parallels to the communication between other HCPs and their patients. In recent years there has been a shift in approach in this literature from describing a consultation style based on traditional and hierarchical, authoritarian interaction based upon distance and expectations of patient compliance to a more patient-centred communication (Levenstein et al, 1986; McWhinney, 1989; Grol et al, 1990; Stewart et al, 2000; Stensland & Malterud, 2001). Some studies still report that HCPs have considerable difficulties in focusing on the patients' situation in their personal contexts (Henriksen & Rosenqvist, 2003). Mead and Bower (2000) discuss the recent interest in patient-centred interaction, arguing that it has evolved from dissatisfaction with the biomedical science to embody a complex set of professional, sociological and political ideas about the doctor-patient relationship and that today many researchers use the concept "patient-centred care" as an indicator of the high quality of the interaction. McWhinney (1989) describes a patient-centred approach as one in which the physician tries to enter the patients' world, in order to see the illness through the patients' eyes. Laine and Davidoff (1996) say that patient-centred care is closely congruent with and responsive to patients' wishes, needs and preferences. Mead and Bower (2000) in their conceptual framework and review of the empirical literature identify five conceptual dimensions in patient-centred care, namely the "biopsychosocial perspective"; "sharing power and responsibility"; "seeing the patient as a person"; "forming a therapeutic alliance"; and "viewing the doctor as a person".

Several current approaches to the interaction between patients and professionals indicate this shift to a more patient-centred approach in the consultations. Examples of frequent approaches labelled in the literature are concordance (Royal Pharmaceutical Society of Great Britain, 1997), shared decision-making (Charles et al, 1997), mutuality (Briant & Freshwater, 1998; Gafaranga & Britten, 2003), partnership (Charles et al, 1999; NHS Executive, 1996), therapeutic alliance (Madden, 1990; Howgego et al, 2003; Reach, 2003), patient participation (Cahill, 1998; Stivers, 2002; Mitcheson & Cowley, 2003), shared responsibility (Graber et al, 2002), involvement (Martin et al, 2001) and empowerment (Anderson et al, 1995). Most of these approaches recognise the importance of involving patients in partnership, coming to an agreement on common treatment goals or assuming the patients' goals and, furthermore, communicating well. The last-mentioned action could for instance be done by discussing treatment and lifestyle questions in a suitable way, by informing but also, letting the patients themselves find out about and suggest possible lifestyle

changes, which in some studies has been shown to be correlated with more lasting health benefits (Arborelius, 1996; Renders et al, 2002). Little et al (2001) conclude that patients' preferences for a patient-centred approach focus first on communication, then on partnership and lastly on health promotion.

Problems in communication have been shown to negatively influence the outcome of care (Stewart, 1995; Barry et al, 2000). The outcome of communication may be dependent on factors such as time for consultations (Andersson, 1995; Goedhuis & Rethans, 2001) and counselling skills (King et al, 2002) but also, attitudes towards patients (Maroney & Golub, 1992; Price et al, 1987; Puhl & Brownell, 2001; Ogden et al, 2001), which can be an obstacle to good interaction and a reason for limited effects of educational efforts.

Contrasting patients' and professionals' perspectives on diabetes, and diabetes care

Paterson (2001b, p 23) defines an illness perspective as being representative of beliefs, perceptions, expectations, attitudes and experiences of what it means to be a person with chronic illness within a specific context. The illness perspective determines how people respond to the disease, to themselves, to their caregivers and to situations that are affected by their illness, such as employment. The professional perspective of diseases, by contrast, determines how the disease affects the body, and focuses on mechanisms, causes, consequences and treatment in order to restore people with illness and their bodies to their "normal state". Health care professionals' perspectives in general form part of a scientific conception or "disease" paradigm while patients experience illness from a life-world perspective (Toombs, 1993; Barry et al, 2001). These perspectives exist, but vary depending on the moment in time and context. For example, an illness perspective is not held only by patients, since professionals may have experiences of illness either themselves or among their relatives. In the same way people with a disease may be inspired by professional perspectives, particularly today when the Internet and other kinds of information technology have made it easy to seek information about diseases, which is often presented from a professional viewpoint. Though patients' and professionals' perspectives on illness may at times meet without confrontation, at other times they clash.

Several studies have compared HCPs' and patients' contrasting perspectives or models of understanding diabetes and diabetes care and many studies report various views of aetiology, symptoms, blood sugar, prognosis and goals for treatment (Loewe & Freeman, 2000; Cohen et al, 1994; Hunt et al, 1998). Loewe and Freeman (2000) report that patients are concerned with external and visible manifestations of the disease, such as amputations and blindness, while

HCPs are more concerned with the underlying processes that have to be counteracted in order to prevent disease progression. Cohen et al (1994) report that patients in their study emphasised difficulties in the social domain and the impact of diabetes on their lives, while health professionals saw diabetes primarily as a pathophysiological problem with impact on the patients' physical well-being. Hunt et al (1998) report that patients evaluated diabetes control in terms of how they felt while practitioners evaluated blood glucose concentrations.

Outcome of interventions

Diabetes education of HCPs and those affected by diabetes in order to facilitate self-management of the disease is considered to play a key role in the prevention of diabetes-related complications. There are many types of outcomes from interventions studied, including changes in metabolic balance, self-management or coping strategies, increased knowledge and quality of life.

Well-being and quality of life have been reported to increase, at least in the short term, following programmes supporting self-management (Steed et al, 2003). Quality of life as well as health outcomes has also been shown to increase as a result of individualized nursing care after education among persons newly diagnosed with diabetes type 2, a multi-method that Whitemore et al (2001) view as cost-effective. Larne and Pugh (1998) point out the importance of long-range goals leading to both well-being and metabolic control among patients, not merely metabolic control.

The effect of interventions, educational or psycho-social, aimed at self-management and improved glycaemic control is, however, reported to be uncertain. Moreover, in many cases the interventions are reported to be poorly described and the metabolic effects in the longer term are discouraging (Norris et al, 2002). In particular, there is lacking evidence of efficiency of traditional didactic education programmes alone for improving glycaemic control (Brown, 1999; Griffin, 1999; Norris et al, 2002).

Despite these facts, knowledge about diabetes is generally viewed as necessary for self-management but is not sufficient to induce behaviour change or improved clinical outcomes in diabetes (Coates & Boore, 1996) even if some studies report effects of traditional education on glycaemic control (Parchman et al, 2003). Also, some treatment strategies such as education given in small groups and focusing on training in coping skills have been reported to improve glycaemic control in the short term (Rubin & Peyrot, 1999; Tattersall, 1985). Organizational interventions that improve regular prompted recall and review of

patients are also reported to improve diabetes management and glycaemic control in the short term (Renders et al, 2002). A current review (Ellis et al, 2004) concludes that face-to-face interaction, cognitive reframing, and self-management programmes with exercise components are predictors of metabolic control. Follow-ups by support groups are also reported to be necessary for more long-range outcomes (Scott et al, 1984; McNabb et al, 1993; Gilden et al, 1989). Larme and Pugh (1998) point to the importance of questioning not only the patient's knowledge but also, the caregiver's attitudes and knowledge, which has to be kept up-to-date with latest developments.

RATIONALE FOR AND AIMS OF THE THESIS

Current results from various studies show that globally the suffering from and costs related to diabetes type 2 and its complications are increasing dramatically (see, e.g., Gray et al, 2000). Effective metabolic control has been shown to significantly decrease the risk for complications (see, e.g., DCCT 36, 1995; UKPDS, 1998; Stratton et al, 2000). As outlined in the previous section, nursing care in diabetes is a complex and difficult but important field of research that may enable people with diabetes to better cope with their illness. However, many nursing interventions are poorly described and the metabolic effects in the longer term are discouraging (Norris et al, 2002). Many researchers emphasise the importance of focusing on the illness perspective generally and also, in relation to specific diseases such as diabetes, of understanding people's beliefs about health and illness since these are related to their self-management. Most research on personal models focusing on how patients understand and interpret their disease/illness is done among first populations such as Mexico-Americans (Luyas, 1991) and Native Americans (Huttlinger et al, 1992) or minority groups such as migrant Yugoslavian (Hjelm et al, 1999) and Arabic-speaking immigrants (Saleh Stattin, 2001). A minority of studies are performed from a Western perspective, in other words, from the perspective of the industrialized world. Despite a great deal of research done on interventions with various methods and caring alternatives the question about how to reach the goals for diabetes care is still not sufficiently answered.

The overall purpose of this thesis was to investigate experiences of diabetes and diabetes care among people with diabetes type 2 and district nurses working within primary health care and responsible for diabetes care.

The specific aims of the studies were to –

- describe personal understanding of illness among people with diabetes type 2;
- illuminate dimensions of psychosocial development among people with diabetes;
- elucidate experiences of clinical encounters in diabetes care as narrated by people with diabetes type 2;
- describe nurses' views of their work with patients in diabetes care; and
- evaluate whether an intervention which focuses on patients' personal understanding of their illness is more effective than is conventional diabetes care with regard to metabolic control, well-being and treatment satisfaction in a group of patients with diabetes type 2.

METHODS

Settings and participants

The study was performed in the Umeå Health Care district which is located in the county of Västerbotten in northern Sweden. At the time of the study (2001) the district had 136 783 residents, 104 512 of whom lived in Umeå, the only town in the region.

Settings

The study was conducted within primary health care, which includes 15 health care centres (HCCs) located both in rural and in urban areas. Three of the papers (Papers I, III and V) report studies performed in patients from four of the HCCs. In Paper V, a group of control patients from four other HCCs is added. One paper (Paper II) is on patients from two HCCs. The remaining paper (Paper IV) reports on research done on nurses from northern Sweden.

Participants and sampling

Papers I, III and V report on the same participants, who were sampled based on their involvement in the intervention study (Paper V). A randomisation was made at a clinical level and patients from four HCCs were allocated to an intervention group and from four others, to a control group. After exclusion of patients not meeting the inclusion criteria (i.e. being Swedish-speaking, being aged between 40 and 80 years, being diagnosed with diabetes type 2 during the previous 2 years and not suffering from severe illness or disabilities) 201 patients remained. The number of participants were estimated and adjusted for the quantitative analyses according to a power calculation based upon their HbA_{1c} levels. We estimated that sub-group sizes of 33 people would have 80% power to detect a difference in HbA_{1c} of 1% between groups and therefore decided to offer all eligible patients (after exclusion) the possibility of participation in order to compensate for possible dropouts. The 97 (48%) patients who declined to participate did not differ significantly in age or gender from those agreeing to participate ($n = 104$; 52%). Forty-four patients (48% women) with a mean age of 63 (SD \pm 9.3) years were allocated to the intervention group and 60 patients (45% women) with a mean age of 63 (SD \pm 9.1) years, to the control group. The groups were judged as equivalent based upon baseline data that did not reveal any significant differences between groups. A flow diagram of the sampling for Papers I, III and V is presented in Figure 1.

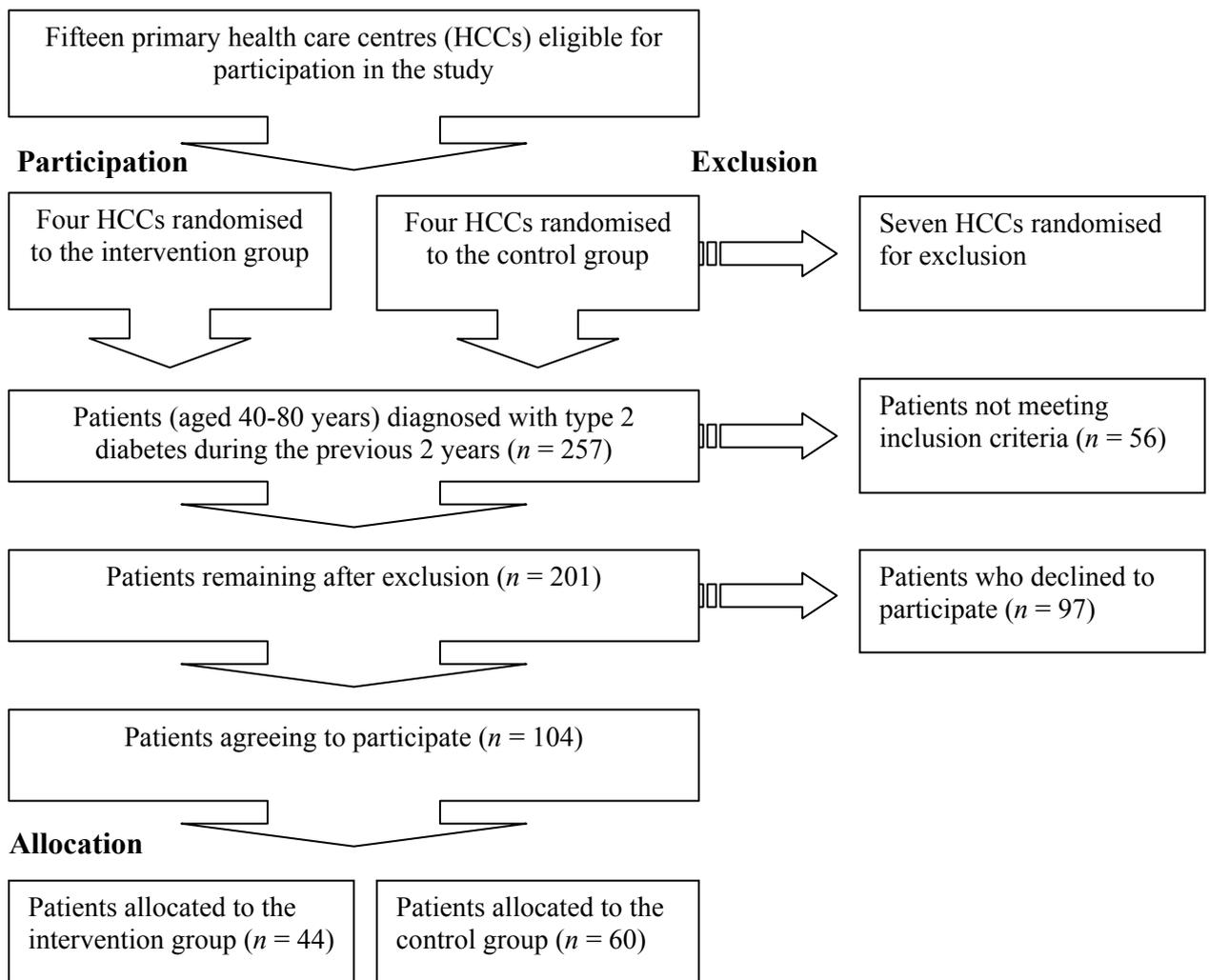


Figure 1. Flow diagram of the sampling.

The sampling of participants for Paper II was based upon an earlier study (reported elsewhere) among patients diagnosed with diabetes type 2. They were patients at two HCCs in the health care district and had (among 154 other patients) participated in a questionnaire survey 3 months previously. A random sample of 16 patients were asked to participate in the interview (Paper II) and ten (60% women) with a mean age of 66 (SD \pm 15.2) years and diagnosed with diabetes during the 13 (SD \pm 8.3) previous years agreed to participate in the study. The six patients who declined to participate did not differ significantly in age or gender from the participants.

The sampling in study IV was convenient as the nurses included were recruited on the first day they started a university course in diabetes care. The 17 female nurses, who all accepted participation in the study, were between 25 and 54 years old and had experience of working in diabetes care for 2–20 years.

Intervention

The time line in the intervention study directed at nurses and patients is illustrated in Figure 2.

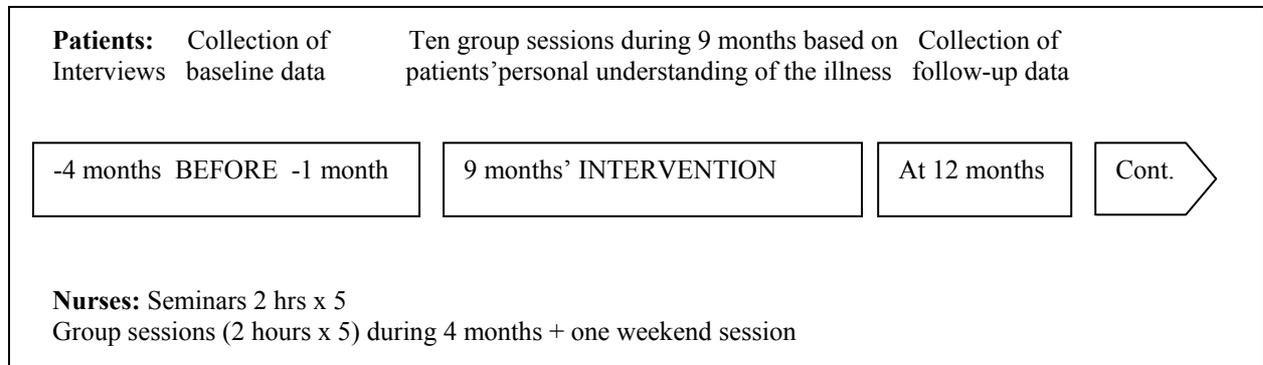


Figure 2. Time line of the intervention study (Paper V).

Intervention aimed at nurses

The intervention directed at the nurses aimed to educate the nurses in theories about diabetes and diabetes care. It further aimed to introduce them to various perspectives on illness experiences and patients' understanding of illness, discussed by reflecting upon the patient interviews, which could be used as a basis for individual care. This part of the intervention was expected to contribute to more long-term effects of the intervention. As a first step in the intervention the diabetes nurses met for five educational group sessions (of 2 hours each). Next they participated in one weekend session (of 16 hours) and five reflective group discussions (of 2 hours each) about the findings of the patient interviews. The nurses did not pay more visits to the participants than to the non-participants in the intervention (in other words, all participants and non-participants were paid one to two visits per year) by the nurses. However, during the visits nurses were encouraged to put more emphasis on the patients' understanding of their illness than on transferring their own professional knowledge.

Intervention aimed at patients

The intervention aimed at the patients in the intervention group included an initial interview about their illness experiences and understanding of diabetes (Paper V). Examples of questions asked were: "When did you get your diabetes?", "Tell me about your experiences of living with diabetes" and "What knowledge do you believe is important for managing the disease?" The

interviews were used in the training of nurses and served as subject for the discussions in the group sessions with the patients.

Patient group sessions

The participants were then invited to ten group sessions (of 2 hours each) over 9 months (September 2001 – May 2002) with the first author (Å.H.) as a moderator. Discussions in the group session were based on the patients’ needs and questions raised from the interviews as well as problems and questions raised during the group sessions. Examples of questions discussed were: “Why do I feel a craving for sweets even though I have high blood sugar?”, “I know how to take my self-tests, but why do I need to take them?” and “My doctor talks about the benefits of exercise, but how can I exercise with arthrosis, and how can I eat foods that are both healthy and tasty?” After each meeting, minutes were taken to summarize the discussions and note down the participants’ requests for discussion points for the next meeting. In Figure 3 the central content of the group sessions with the patients is summarized.

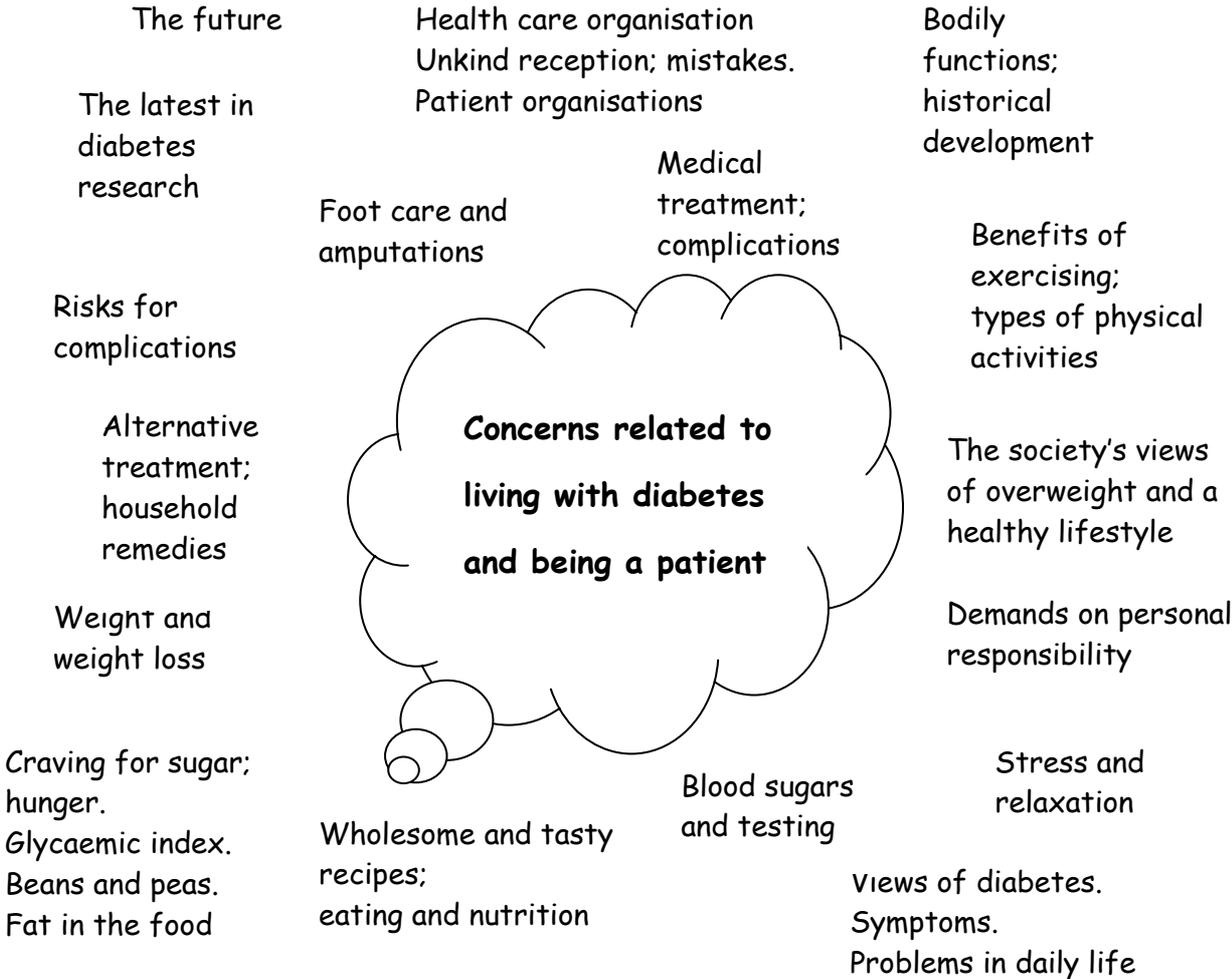


Figure 3. Key issues discussed in group sessions.

Data collection and analyses

To reach the aim of the thesis both qualitative and quantitative methods were used. Table I presents an overview of the methods of data collection and analysis.

Table I. Summary of data collection methods and analysis.

Paper	Data collection method	Analysis method
I	Narrative thematic interviews	Content analysis
II	Semi-structured interviews	Content analysis
III	Narrative thematic interviews	Content analysis
IV	Focus group interviews	Content analysis
V	Questionnaires	Statistics
V	Laboratory measurements	Statistics
V	Physical measurements	Statistics

Interviews (Papers I–IV)

Narrative thematic and semi-structured interviews (Sandelowski, 1991; Kvale, 1997) were conducted individually and in focus groups (Kitzinger, 1995). The overarching purpose of the patient interviews was to elucidate the patients' illness experiences related to living with diabetes. Illness narratives give voice to both the suffering and the life-world context of illness (Hydén, 1997). A qualitative interview, according to Kvale (1997, p. 25), is a specific form of conversation aimed at understanding dimensions of the interviewee's life-world. The overarching purpose of the focus group interviews was to elucidate variations in experiences as well as group thinking among nurses about patients with diabetes and diabetes care. The interviews were tape-recorded and transcribed verbatim for later analysis.

Questionnaires (Paper V)

Besides evaluating the nursing intervention by measuring the metabolic parameters, we considered it important to evaluate people's experiences of symptoms, well-being and treatment satisfaction. Four questionnaires were used in the fifth and last study and the motive for using the questionnaires described below is that they are considered to be reliable and valid and that they measure important aspects that needed to be evaluated in the intervention. Furthermore,

they are considered suitable since they are specially designed for people with diabetes type 2. The Sense of Coherence (SOC) scale SOC 13 was chosen because of the strong correlation between SOC and patients' evaluations of disease-specific health and general well-being as well as their ways of coping with illness, as shown in several studies (Nilsson et al, 2001; Kivimäki et al, 2000; Sandén-Eriksson, 2000). Recent results suggest that a strong sense of coherence may confer some resilience to the risk of chronic disease and a reduced risk of mortality (Surtees et al, 2003).

Sense of Coherence scale

The 13-item SOC scale with a possible score of 13–91 was developed by Antonovsky (1987) to measure the SOC which is seen as a global orientation towards life and includes three dimensions, comprehensibility, manageability and meaningfulness. A higher score is construed as a stronger SOC, but extremely high scores indicate rigidity (Antonovsky, 1987). The short-version 13-item SOC has been found to be reliable (Cronbach's α 0.74–0.93) and valid (Antonovsky, 1993; Langius & Björvell, 1993).

Diabetes Symptom Checklist

The 34-item, revised Diabetes Symptom Checklist (DSC-R), with a possible score of 34–170, was developed by Grootenhuis et al (1994) to assess the burden of physical and psychological symptoms related to diabetes type 2. The checklist includes the following sub-scales: psychology (fatigue), psychology (cognitive), neurology (pain and sensory), cardiology, ophthalmology, hypoglycaemia and hyperglycaemia. In the DSC-R a higher score is construed as a higher load of symptoms. The questionnaire has been found to be valid, reliable (Cronbach's $\alpha = 0.94$) and responsive to change. Recent evidence, albeit weak, suggests that higher scores are associated with poorer glycaemic control (Van der Does et al, 1996).

Well-being questionnaire

The 22-item Well-Being Questionnaire (WBQ-22), with a possible score of 0–66, was developed by Bradley and Lewis (1990) to assess mood in relation to diabetes management. The questionnaire includes sub-scales providing a measure of depressed mood, anxiety, energy and positive well-being for persons with diabetes. In the WBQ-22 a higher score is construed as a higher degree of well-being. Both the questionnaire in total and its sub-scales have been found to be reliable (Cronbach's $\alpha = 0.65$) and valid (Bradley, 1994a).

Diabetes Treatment Satisfaction Questionnaire

The eight-item Diabetes Treatment Satisfaction Questionnaire (DTSQ), with a possible score of 0–36, includes two items on experiences of hypo-/hyperglycaemia, which are not summarised in the total scores. The

questionnaire was developed by Bradley and Lewis (1990) to assess treatment satisfaction. In the DTSQ a higher score is construed as a higher degree of treatment satisfaction. The DTSQ has proved to be highly reliable (Cronbach's $\alpha = 0.86$), with good construct validity, sensitivity to change and discriminatory power (Bradley, 1994b).

Laboratory/Physical Measurements (Paper V)

Haemoglobin A_{1c} levels were measured using Tosoh HLC-723 GHbV (A_{1c} 2.2; Tosoh, Tokyo, Japan) automated high-performance liquid chromatography (HPLC) for glycosylated haemoglobin measurements. The normal range for HbA_{1c} is 3.6–5.3% while a HbA_{1c} level <6.5% is the Swedish treatment target for good metabolic control. Total cholesterol, high-density lipoprotein (HDL), low-density lipoprotein (LDL) and triglycerides were measured with standard clinical laboratory methods. Blood pressure (BP) was taken manually by trained nurses, with the patient in a sitting position after a minimum of 5 minutes' rest. Weight was measured and body mass index (BMI) calculated as weight (kg)/height (m)².

Data analysis

Content analysis (Papers I–IV)

Content analysis was used in studies I–IV. We found the method appropriate because it is suitable for larger amounts of text. The method has its roots in journalism where it has been used for tasks such as analysing propaganda (Baxter, 1991). Downe Wamboldt (1992) states that qualitative content analysis is designed to describe phenomena of interest for a certain purpose. In the method it is accepted to use a certain framework within which or perspective from which to analyse data (Downe Wamboldt, 1992). In qualitative content analysis, according to Graneheim and Lundman (2004), both manifest messages (i.e. content close to the text) and latent content (i.e. underlying messages) are highlighted. The method includes analysis in different steps resulting in identification of categories and possibly, themes. As an example of the procedure, one part of a content analysis is outlined in Figure 4. The steps passed through in the data collection and analyses are described for each paper.

Theme	Categories	Sub-categories
Dissatisfaction based on feelings of being ignored and feeling unwelcome	Feelings of being alone with the suffering	Did not get any attention Was not taken seriously Did not get help with the problems
	Feelings of disturbing the personnel	Sought help at the wrong time Disturbed the personnel in their work The problem was viewed as not important enough
	Feelings of not being trusted	Was compared with other patients Was not listened to Was viewed as a hypochondriac

Figure 4. Part of a content analysis, an example.

Paper I

This paper presents interviews with 44 patients with diabetes type 2. The participants were asked to talk about their life with the illness and their experiences as well as their reflections about the illness. They were also asked to reflect on their expectations of diabetes care and on what they most needed from health care in order to manage to live with diabetes and the demands related to it, all information that was used for the intervention. The interviews took place in the participants' homes (occasionally at their workplace) and lasted for about 45–90 minutes each. The transcribed text from the 44 interviews was combined into one text constituting the unit of analysis. The text was read through several times and discussed by the research team in order to grasp the overall content. The first, superficial interpretation was that the narratives dealt with the aspects of getting, coping with and living with diabetes. The text was then divided into meaning units, constellations of words or statements that related to the same central meaning, by the first author using NVivo 2.0 (QSR International Pty Ltd). The meaning units were condensed and coded inductively inspired by the initial discussions about the overall content of the text. The purpose was to put aside known theories about personal understanding or explanatory models of illness and instead let the text speak for itself. Other members of the research team coded parts of the text to confirm that the codes appeared to be logical and were consistent with the content. Minor discrepancies were discussed until consensus was achieved (Lincoln & Guba, 1985). The codes were consolidated into tentative categories and sub-categories, which were organised into a scheme with a time perspective. The findings were presented to the participants during the group sessions and they expressed their recognition, a reaction that was considered to strengthen the credibility of the findings.

Paper II

This paper presents interviews with ten patients who 3 months previously had completed a questionnaire covering Erikson's (1997) theory about the eight psychosocial stages humans develop through in life. Of those who filled in the questionnaire, ten were randomly selected to participate in an interview about their life histories including their experiences of having diabetes. The interviews took place at the participants' homes and lasted for 40–75 minutes. The transcribed text from the ten interviews was brought into one text constituting the unit of analysis, which was read through in order to obtain a sense of the text as a whole. Thereafter the text was read in detail and roughly sorted into domains covering the three areas of trust, identity and integrity. The three domains were analysed one by one by the first author, including identification of meaning units, which were condensed in order to make the text shorter but retain its core messages. In this close analysis of the text some meaning units were moved to another domain. The manifest messages (i.e. the explicit messages close to the text within the condensed meaning units) were then abstracted and labelled with codes. Parallel with this process the contextual meaning of the original text included latent messages (i.e. ironies or implicit messages) as interpreted and coded in concordance between the researchers. The various codes in the three domains were compared on the basis of similarities and differences and sorted into schemes labelled as categories and sub-categories. Furthermore, themes appearing throughout the categories, which were interpreted as underlying messages of the abstracted categories, were identified.

Paper III

In this paper I present interviews with 44 patients with diabetes type 2. Apart from the area of questioning presented in Paper I, the interviewees were asked to talk about their experiences of diabetes care and encounters with caregivers. The interviews took place in the participants' homes (occasionally at their workplace) and lasted for about 45–90 minutes in total. At the beginning the transcribed text from the 44 interviews was combined into one text. Then, since Papers I and III are based upon the same interviews, the text that dealt with the patients' narratives about their experiences of encounters in diabetes care was separated from the text by the second author. After reading the text in order to obtain a sense of the text as a whole, the text was read in detail. Meaning units were identified and manifest content, or messages close to the text, was condensed in order to make the text shorter but with retained core messages while latent messages, or ironies or implicit messages, were interpreted and condensed in concordance between the researchers. Then, the condensed meaning units were abstracted and labelled with codes. At the same time the narratives about the experiences were compared with how the experiences were reflected upon by the participants and sorted into schemes. Thus, after

considering the meaning from the original text, it was divided into categories and sub-categories. The categories were further discussed by the research team in order to reject or accept the categorisation and seek agreement between the researchers, sometimes leading to refinement of the scheme of categories and also, to the identification and formulation of themes. The themes were interpreted as underlying or latent messages of the abstracted categories.

Paper IV

This paper presents focus group interviews with 17 female nurses divided into two groups on the day they began a university course in diabetes care. The nurses were all working in diabetes care in community care, primary health care or hospitals. The interviews dealt with their views on working with patients in diabetes care including attitudes towards patients and management of diabetes. The interviews took place at the author's workplace and lasted for about 90 minutes each. The transcribed text from both focus group interviews was read through in order to obtain a sense of the text as a whole and then brought together and sorted into different areas of questioning by the second author. Next, meaning units were identified and manifest messages were condensed while latent messages were interpreted by the members of the research group and condensed, which made the text shorter but kept its core messages. The condensed meaning units were then abstracted and provided with codes. The various codes were compared on the basis of similarities and differences and sorted into schemes within categories and sub-categories. After further studies of the categories deriving from the structural it was possible to identify five abstracted themes running through various categories, interpreted as underlying or latent messages.

Statistical analyses (Paper V)

Paper V presents statistical analyses of baseline data as well as data from 1-year follow-ups in the intervention and control groups. The data consisted of scores for questionnaires (DSC-R, SOC 13, WBQ-22, DTSQ), laboratory tests (HbA_{1c}, total cholesterol, HDL, LDL), BP and BMI. Comparisons between groups as well as changes within groups were analysed. Proportions were compared using chi-squared tests. Means between groups were compared using an independent-sample *t*-test or Mann-Whitney's test where appropriate. Changes in means within groups were compared using the paired-sample *t*-test. Hierarchical analysis of variance (ANOVA) was used to analyse treatment effects when HCC was nested within treatment group. Two-sided significance tests were used throughout. P-values <0.05 were considered to be statistically significant.

Methodological considerations

With the study's aim in mind we considered it necessary to use quantitative as well as qualitative methods. Among the qualitative methods interviews with a narrative character were found to be most appropriate since they permitted us to acquire knowledge from people's life-world experiences. In this work the interviewer was viewed as an integral part of the investigation and the interview situation therefore required understanding and co-operation between the researcher and the participants, resulting in mutual and contextually bound texts. In this work the view of knowledge deriving from interviews is in line with the method proposed by Lincoln and Guba (1985) and Mishler (1986), in which knowledge is constructed by both the researcher and the interviewee during the process of inquiry. One problem that may arise in an interview situation is the potential risk of the interviewer directing the interviewee towards particular ways of answering, a problem we tried to counteract by being aware of the phenomenon during the interviews. Other problems arising during the interviews are that the interview could become superficial or even untrue, a problem we tried to avoid by creating a permissive climate and helping the interviewee to feel free to relate, relying on confidentiality (see, e.g., Lindseth & Norberg). The interviews in Papers I and III were too numerous, according to the aim of the papers, but were a prerequisite to accomplishing the intervention, which in turn was based on a power calculation. After about 20 interviews we found that not much new knowledge was being added to the knowledge already gained. To reach the study aim, however, we analysed all 44 interviews. It is also possible for an analysis to become too narrow due to the amount of text analysed; however, our findings have contributed to some new knowledge within this research area. The qualitative content analysis in Paper I is partly inspired by Grounded Theory, since the analysis was in progress during the time of the interviews and thus gave inspiration for questioning around themes that emerged in several interviews, which we found to be a benefit.

The intervention study (Paper V) consisted of participation in support groups during 9 months, which represents a significant time commitment, particularly since a lot of patients were still working. This could explain the high rate of people declining to participate (48%). Furthermore, the intervention included several questionnaires, which could also be viewed as time-consuming to complete. However, the baseline data did not reveal any significant differences between the intervention and control groups and neither did we find any disparities between the participants and the non-participants regarding age or gender. The randomisation of primary HCCs (and not at an individual level) was a limitation that may have contributed to inappropriate sampling and selection biases, but was necessary because of the intervention design (i.e. the necessity of keeping the diabetes nurses from the groups separated in order to reduce a

potential spill-over effect). However, we believed that the method of analysis, hierarchical ANOVA with HCCs nested, could handle some of the problems. Moreover, it would have strengthened the thesis if the participating nurses' and patients' views of the intervention had been requested.

FINDINGS

The findings from studies I–III elucidate experiences of living with diabetes type 2 including getting care. Findings from study IV elucidate how nurses working in diabetes care view their work with patients. Finally, findings from Paper V, which is the only quantitative study, help us evaluate whether care based upon patients' concerns and understanding of living with diabetes is more effective than conventional diabetes care.

Paper I

In Paper I we investigated how people with diabetes type 2 understand their illness. The participants' descriptions included earlier experiences as well as expectations of the future. The findings are presented in six categories. The category *image of the disease* included aspects such as recognition, naturalness, seriousness and endurance. The category *meaning of the diagnosis* included aspects such as demands, advantages, and influence on identity. Demands dealt mostly with the necessity for a change of habits. Among the advantages was the ability to experience the diagnosis as a starting point for a new, healthier life. Influence on identity seemed largely to be related to feelings of blame or stigmatization. The category *integration of the illness* was described as incorporation and reconciliation. Incorporating the illness into daily life was described as the demanding task of taking control of and, further, establishing personal routines for handling the new situation. Reconciliation, or coming to terms with the disease, was interpreted as viewing diabetes from a life perspective and maintaining a sense of equanimity. The category *space for the illness* included the aspects value and priority. Personal value was related to how one has possibilities to use time and energy for self-care activities. Priority dealt with giving priority to diabetes among other problems or diseases. The category *responsibility for care* was described by the aspects engagement in illness management but also included other people and society and/or God. By "power" was meant self-chosen responsibility, which is described as connected with trust in oneself. Finally, the category *future prospects* dealt with views, plans and hopes for the future. Diabetes was not separated from other future prospects though the disease was not spoken about much. Concerns about the future had a central place in the narratives.

Paper II

The way people with diabetes describe their psychosocial maturity is reported in Paper II. The findings resulted in a dichotomy between positive and negative sides of the categories *trust*, *identity* and *integrity*. The participants' descriptions of their positive maturity in trust, identity and integrity were impressed by feelings of own *activity* and *involvement*, interpreted as themes, while their descriptions of a negative maturity were impressed by the themes *passivity* and *alienation*. Qualities that were considered important for maturation were *understanding*, *capacity*, *purposefulness* and *fortitude*. The findings concerning positive psychosocial maturity are given in Figure 5 below.

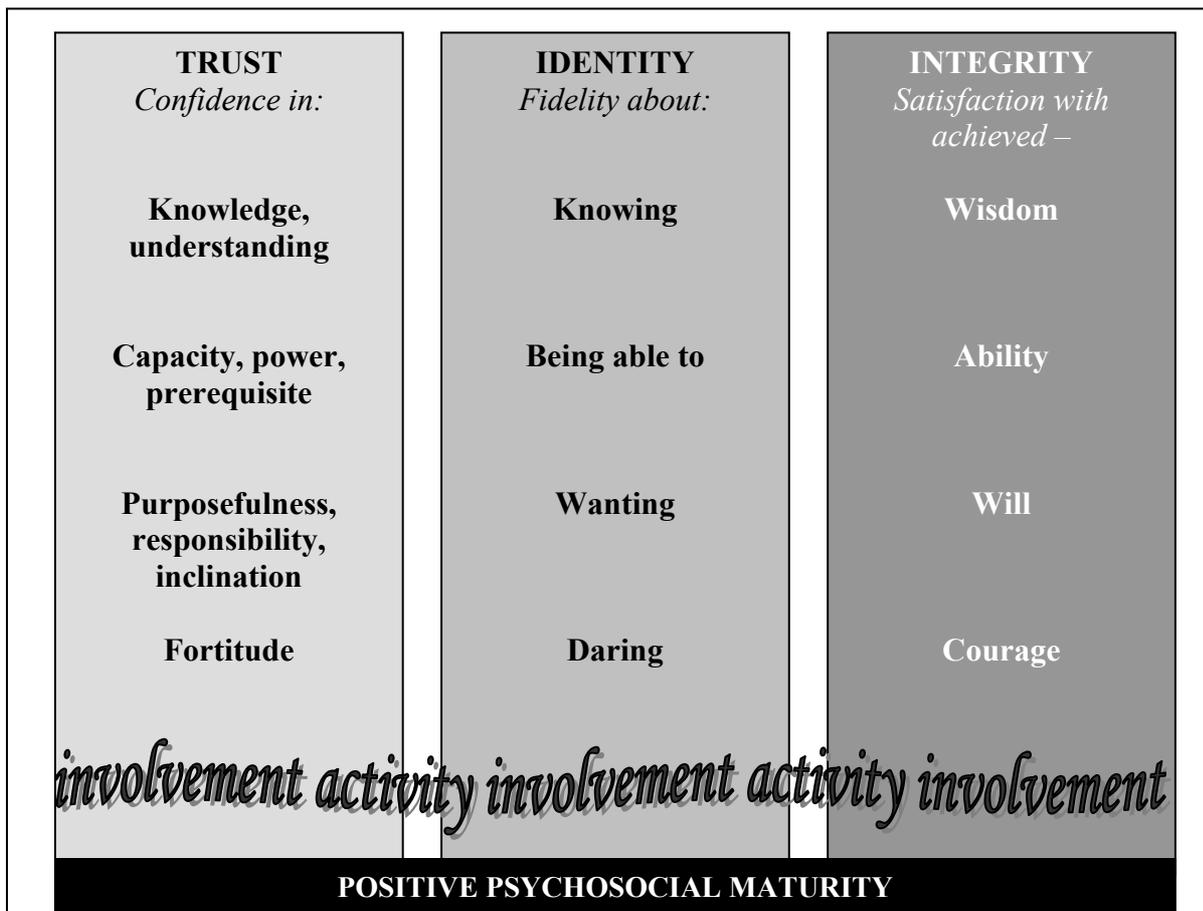


Figure 5. Positive psychosocial maturity, as described in Paper II.

Paper III

In Paper III we studied experiences of clinical encounters among patients with diabetes type 2, which were formulated into the following themes: being in *agreement v. in disagreement about the goals*, in which agreement during the clinical encounter was interpreted as satisfying while disagreement was interpreted as dissatisfying. Agreement resulted from encounters with professionals experienced as sensitive to and accepting patients' own goals and also, as trying to understand factors such as the reason for limited resources or the basis for possible lacking motivation on the part of the patient. Disagreement

emerged from experiences of encounters in which HCPs had goals seen as too high for lifestyle changes and other patient behaviour, goals that were sometimes not in harmony with the patients' own resources, resulting in dissatisfaction with the encounter. The theme being *autonomous and equal v. feeling forced into adaptation and submission*, in which autonomy and equality were related to a satisfying encounter, was exemplified by feelings of permission and autonomy. In such encounters the professional expressed empathy and an understanding of the work associated with self-management of diabetes. Feelings of adaptation and submission resulted from encounters interpreted as dissatisfying, which were exemplified by the professionals' efforts to reshape them into a healthier lifestyle, which sometimes were seen as pointers. The theme *feeling worthy as a person v. feeling worthless*, in which "worthy" was interpreted as satisfying, emerged from narratives about encounters where the patients were recognised as persons with both weaknesses and strengths, not merely as patients. Feeling worthless was interpreted as dissatisfying and was exemplified by experiences of encounters in which professionals used their professional knowledge as a powerful tool to rebuke them, and in which they felt the professionals viewed diabetes as more interesting than the patient. The theme *being attended to and feeling welcome v. being ignored*, in which "being attended to" was interpreted as satisfying, emerged from narratives about professionals who paid attention to the patients and were friendly and welcoming, which gave them a feeling of trust and an experience of co-operation. "Being ignored", on the other hand, was dissatisfying and wounded and insulted the patients. Lastly, the theme of *feeling safe and confident v. feeling unsafe and lacking confidence*, in which "safe" and "confident" were interpreted as satisfying, was exemplified by experiences of encounters that made the patients feel secure, for example in in-patient care. Experiences of feeling unsafe and lacking confidence were interpreted as dissatisfying and emerged from narratives about clinical encounters in which the professionals were quite uncertain and sometimes lacked competence, had antiquated opinions or gave mainly routine information.

Paper IV

Nurses' views of their work with patients in diabetes care are reported in Paper V. The findings are presented in five themes, the first of which is *Perspectives on illness and caring are not easily integrated into views of disease and its treatment*. In the discussions the nurses frequently separated "treating" from "caring" and the concepts seemed hard to integrate. Though difficult, the perspectives of treating and caring were sometimes combined when the nurses considered both perspectives. The second theme, *Nurses view their knowledge as more important than the patients' knowledge*, focuses on the nurses' view of their own priorities and preferences as being more important than the patients' preferences, based upon their own "superior" knowledge. The theme dealt with

the nurses' "superior" knowledge about treatment goals, appropriate blood sugar levels and appropriate self-care and the patients' limited knowledge about long-term risks and complications. The nurses regarded self-care as very important and said they became frustrated when the patients did not value it as highly. Many of the nurses said that their intention of establishing meaningful contact with a patient had often been spoiled at the first consultation owing to the gap in knowledge between them and the patients leading to conflicting goals for self-care. The third theme, *Nurses' conscience is challenged by some of their nursing decisions* revealed that they were aware that rebuking the patients sometimes was burdensome for them. In the same way, however, they defended their decisions as they also knew that if they did not rebuke their patients the patients would get complications in the future; also, their education had influenced their standpoints. On the other hand, deviations from the guidelines and recommended blood sugar levels, on the basis of meeting the patients' individual needs, also caused the nurses moral doubts. The fourth theme, *The individuality of each patient is undermined when patients are regarded as a collective group*, deals with how the nurses described patients more negatively, with negative characteristics, and also talked about their insubordination when they regarded them as a collective group. For example, problematic and non-compliant patients were labelled "smokers", "overweight people", "liars" and "patients who do not take responsibility for their self-care". The nurses we interviewed described how they often based their nursing actions upon the patients' affiliation to a certain group. However, when they described individual meetings with patients, the nurses also talked about each patient's uniqueness and individual problems, which showed that they also valued patients positively and with empathy. The fifth and last theme, *Nurses are confirmed in their role of nurses by patients who assume a traditional patient role*, dealt with how nurses are confirmed in their professional roles by patients who behave in a subordinated way and express their need for support, and how uncomfortable nurses may feel about not being needed. The nurses furthermore described that they were more comfortable when they had more knowledge than the patients as this increased their professional power to influence the patients. They also expressed their doubts about an equal and mutual relationship between the caregiver and the patient.

Paper V

An evaluation of the nursing intervention study is given in Paper V. The intervention included one patient interview and ten group sessions for patients, addressing topics for discussions related to the patients' personal understanding of illness. The mean attendance rate for the ten patient group sessions was 74%. The idea for the intervention was inspired by the literature about illness experiences, personal models and patient centredness as well as literature about patient satisfaction with care. The intervention also included the diabetes nurses

involved in their care, who were educated in theories about illness/wellness experiences and participated in group sessions in which various caring strategies related to the patient interviews were reflected upon, which was expected to affect the intervention in the longer term. At baseline no significant differences were found between the intervention and control groups with regard to sex, type of treatment, age, HbA_{1c}, BMI, BP, cholesterol, HDL, LDL and triglycerides. Nor were there any significant initial differences between the groups concerning sense of coherence, experienced treatment satisfaction, well-being, or diabetes symptoms.

At follow-up, however, significant changes were seen *within the groups* regarding HbA_{1c}, BMI, cholesterol, and treatment satisfaction during the intervention period. Haemoglobin A_{1c} was decreased from 5.7% to 5.4% (SD ± 0.7) in the intervention group while there was an increase from 5.8% to 6.4% (SD ± 1.1) in the control group (Table II). Body mass index was decreased from 29.4 to 28.7 (SD ± 4.6) in the intervention group (Table II); also, there was a decrease in total cholesterol from 5.6 mmol/l to 5.3 mmol/l (SD ± 1.2) (not shown in the Table). By contrast, no significant improvements were seen in the control group. Other parameters such as BP, HDL, LDL and triglycerides did not show any significant changes within the groups. The DTSQ scores were significantly increased from 27.2 to 29.6 (SD ± 5.7) in the intervention group, but not in the control group. Well-being (WBQ-22) and diabetes symptoms (DSC-R) were not significantly changed at follow-up.

When comparing the intervention and control groups there were significant differences in HbA_{1c}, HDL and triglycerides *between the groups* at follow-up (Table II). There was also a tendency towards a difference in BMI, though this was not significant ($p = 0.08$). No other parameters differed between the groups at follow-up (Table II). A hierarchical ANOVA with HCCs nested within treatment group revealed that sex, age, BMI, lipids, treatment and a treatment upgrade did not influence the treatment effects during the intervention period.

In conclusion, at the 1-year follow-up the intervention that was based upon the patients' personal understanding of illness and the topics they related to it, which were discussed among patients and their nurses in support groups, was found to be effective in terms of metabolic control and treatment satisfaction compared with the control group.

Table II. Follow-up data, with differences from baseline data shown.

	Control (<i>n</i> = 60)	Intervention (<i>n</i> = 44)	Treatment effect	Difference (95% CI)	P-value	P-difference¹
	mean ± SD	mean ± SD	mean difference	%		
HbA _{1c} (%)	6.4 ± 1.1	5.4 ± 0.7	0.94	0.58–1.29	0.005	<0.000
HDL (mmol/l)	1.18 ± 0.15	1.33 ± 0.38	0.15	0.01–0.29	0.001	0.029
Triglycerides (mmol/l)	2.21 ± 0.93	1.69 ± 0.62	0.52	0.19–0.83	0.001	0.002
BMI	30.7 ± 6.0	28.7 ± 4.6	2.03	0.09–4.14	0.08	0.105

¹Adjusted for baseline characteristics HbA_{1c}, BMI, lipids, age, sex, treatment and treatment upgrade. BMI = body mass index, calculated as weight (kg)/height (m)²; CI = confidence interval; HbA_{1c} = haemoglobin A_{1c}; HDL = high-density lipoprotein; SD = standard deviation.

DISCUSSION

The vital importance of beliefs about health, illness, cure and control is a predictive factor for the outcome of dietary and exercise management (Hampson et al, 1990; 1995), which is the cornerstone of non-pharmacological treatment of diabetes (Agardh et al, 2002; WHO, 2002). People’s beliefs and understanding of their illness are mainly studied in illness narratives elucidating those components the patients believe to be central to their experience of the illness and its management. In this thesis “personal understanding of illness” – the complex intertwining of thoughts, feelings, explanations and understanding involved in the illness experience, is used to name what other researchers refer to as “explanatory models” – the lenses through which people can make sense of illness (Kleinman, 1988); “common sense models” – a proximal determinant of both the emotional and the behavioural response to the illness (Leventhal et al, 1980); and personal models – representations of people’s emotional response to disease and treatment (Hampson et al, 1990).

The personal meaning of illness and disease may be reflected by elucidating people’s personal understanding of illness. It reflects the patient’s perspective, that is, the voice of the patient’s life-world. According to Mishler (1984, p 104), “voice of the life-world” refers to the patient’s contextually grounded experiences of events and problems in his or her life, expressed as reports and descriptions of the world of everyday life from the perspective of a “natural attitude”. The term “natural attitude” is a term that phenomenologists use to describe taking the everyday world for granted and assuming it to be only what it

is. In this mode of attention and awareness, people unquestioningly accept the life-world and rarely consider that it might be otherwise (c.f. Toombs, 1993).

Professional understanding of illness (i.e. the voice of medicine) reflects a “scientific attitude” in which the meaning of events is provided through abstract rules that serve to explain clinical signs, for example, by removing them from particular personal and social contexts (Mishler, 1984, p. 104). Kay Toombs (1993) describes the physicians’ and patients’ different perspectives on illness and diseases as originated in different worlds. For example, the “diagnosis” may from a physicians’ perspective be seen as a solution as they have fit all pieces together in a puzzle, while it for a patient newly diagnosed with a chronic illness such as diabetes, it may be seen as a starting point in a life-long adaptation. Toombs argues that both perspectives are necessary, but as professionals we need to be aware of the similarities and differences between them. Professionals’ engagement in patients’ life-worlds is shown to improve the outcome of care and further, make treatment more human since the presumption is to view patients as unique human beings (Barry et al, 2001). A narrative illness story, according to Frank (1998), is a perfectly adequate representation of the individual experience of illness and is therefore suitable for studying personal understanding of illness. However, when reduced to a clinical technique, it loses force. Furthermore, the narrative is shared among the professional and the ill person and can open a mutual relationship. The best clinical gift to the ill person is therefore to listen to these stories, but not to fix them (Frank, 1998, p. 210).

The main findings underlines that understanding of illness and views of care differs between patients and nurses in diabetes care and furthermore, the results demonstrate that an intervention involving patients and their nurses, based on patients’ personal understanding of illness is effective with regard to metabolic control and treatment satisfaction.

Personal understanding of illness

The findings about personal understanding of illness revealed that most people with diabetes experience and understand illness in a natural way, which differs somewhat from a professional’s scientific attitude. The patients’ understanding of illness in the current situation included experiences of the past and expectations of the future. The individual meaning of diagnosis was separated from the integration of the illness, which is influenced by the social contextual meanings of illness such as views of responsibility for care and space for the illness in daily life. Earlier research on personal models has identified components such as identity/labels of the disease, causes, consequences, disease course and cure or control (Lau et al, 1983; Cohen et al, 1994; Hampson et al,

1990; Allan et al, 1998). Our findings possibly contribute some new ideas to the knowledge about personal models because they highlight aspects not previously mentioned such as separating the meaning of diagnosis from the integration of the illness. Integration was described as incorporation and reconciliation, which does not imply acceptance. A great deal of the literature has pointed to the importance of acceptance of diabetes (Francioni & Silva, 2002; Zauszniewski et al, 2002; Karhila et al, 2003), which by us are suggested to be in concordance with accepting a patient role or a sick role (c.f. Laine, 1997) and thus diminishes the power of the patient in relation to the professional. The components previously described within personal models have, despite their roots in a patient's life-world, strangely been labelled similar to (and possibly influenced by) concepts used within traditional medical models, such as diagnosis, causes, complications, prognosis and treatment. It should be emphasized that our findings on personal understanding reflect the Swedish context since other researchers have paid attention to deviances in personal models due to ethnicity (Saleh Stattin, 2001; Chesla et al, 2000; Hjelm et al, 2003) and gender (Koch et al, 1999; 2000).

The intervention

Our findings about personal understanding formed the basis of our intervention study. The patients within the intervention group participated in support groups concerned with their understanding of the illness. Their diabetes nurses were educated, and participated, in support groups on the same topic. The patient groups (i.e. the intervention group and the control group) were considered equivalent based upon baseline data. The 1-year follow-up revealed that the intervention was effective in terms of improvements in metabolic control and treatment satisfaction, which is satisfying because interventions aimed to improve self-management of the diabetes have been reported to be deficient with regard to metabolic control, at least in the longer term (Norris et al, 2002).

What could possibly be the reason for the positive effects, then? One interpretation is that a focus on thoughts, feelings, explanation and understanding involved in the illness experience to a higher degree empowers people to reflect upon and make decisions about self-management. Another interpretation is that participation in support groups, which is shown to be effective by some studies (Gilden et al, 1992; Alley & Brown, 2002; Hill & Gilroy, 2002) could have effects on self management, since it give people the opportunity of meeting other persons affected by the same disease, and of reflecting upon their stories. The length of the intervention is another possible explanation for the effect, since giving support to patients in follow-ups has been shown to affect the outcome of education. The continuity within the

intervention, with one person co-ordinating the group sessions, which led to a close relationship between the nurse and the patients is another explanation for the effect. On the other hand, person-dependent effects and project enthusiasm may be a limitation. One comment on the design is the multi-method used, by which is meant the method of directing the intervention at the patients as well as at their nurses, a technique rarely described in the literature. This design may explain some of the effects and may possibly also lead to prolonged positive effects. A multi-method design may, however, be problematic since the relationship between the different parts of the intervention and the outcome is not clear. The non-participation rate is another limitation. A reason for the non-participation rate could be that the intervention was time-consuming and that many patients were still working. Other limitations of the study design are randomisation at a clinical level and the fact that the study became a total investigation without a sampling procedure at an individual level. The randomisation at a clinical level was done so as to separate the nurses from the various HCCs. Based on the power calculation we needed 33 patients in each group to prove a significant difference of 1% in HbA_{1c}. The total number of patients eligible for participation was too low to sample, and therefore it was decided to offer entire participation, which resulted in group sizes judged as adequate.

Patients' and nurses' views of care

Narratives about clinical encounters give opportunities for professionals to listen to patients' experiences of care. Our findings revealed that patients with diabetes were satisfied with those encounters in which they were listened to, were treated as equals and were respected for their choices; furthermore, in which they were treated as persons, not merely as patients or cases with a "disease". Comparing patients' perspectives on clinical encounters with nurses' perspectives on their work with patients in diabetes care elucidates that nurses' perspectives somewhat contradicted the aspects patients found important in clinical encounters. For example, the nurses were confirmed by patients who assumed a traditional patient role and they also viewed professional knowledge as more important than patients' knowledge, which could be contrasted to patients' preferences for those encounters in which they were treated as equals and respected for their choices. Furthermore, the findings revealed that the nurses found modern care too liberal, which implicitly means that the nurses' role has become less powerful. This could be explained in part by nursing education in the past, which was based on authoritative medical competence, and which educated district nurses to become a kind of moral guardian, whose task it was to instruct the population to behave well and thus restore health (see, e.g., Andersson, 2002). This tradition could also explain some of the nurses'

standpoints. Some nurses viewed themselves as being equipped with the “right” kind of knowledge, which should be transferred to the patient in order to maintain health. The findings could also be interpreted to be a result of the nurses’ difficulties in finding a balance between the different paradigms disease and illness, making it problematic to make ethical choices as this challenges their conscience.

According to a review of the empirical literature, patient centredness in care includes five conceptual dimensions (Mead & Bower, 2000). These are the biopsychosocial perspective, sharing power and responsibility, seeing the patient as a person, forming a therapeutic alliance and viewing the doctor as a person (Mead & Bower, 2000), which is in line with our findings about patients’ experiences of satisfying clinical encounters. Furthermore, our findings about dissatisfying encounters to a high degree coincide with other research identifying negative experiences of care as dehumanising, objectifying, disempowering and devaluing (Coyle & Williams, 2001). These words, which describe negative experiences of care, have an effect on me and probably on most nurses and doctors, and draw attention to the importance of reducing such experiences among patients. Bury (2001) has identified a renewed emphasis on the value of holistic medicine and of listening to the patient and proposes that a recent, powerful “democratic impulse” has led to a reduction in hierarchical relationships, including in the medical sphere. It seems that the nurses in our study, despite their awareness of modern influences in the area of patient-professional relationships, had not sufficiently adapted to provide patient-centred diabetes care, which would involve viewing illness through the patient’s eyes and sharing power and responsibility (McWhinney, 1989; Laine & Davidoff, 1996; Mead & Bower, 2000). Instead, it appears that they still advocated a patient-professional relationship based upon compliance and adherence, which may be seen as quite old-fashioned. Armstrong (1986), among others, describes the ambiguity of a professional expansion among physicians (and other professionals) to “patient-based” and comprehensive health care, which requires a redefinition of the professional role from preoccupation with a reductionist model of illness to a more patient-centred approach.

Summary and clinical implications

The point of departure for my research was Lundman’s (1990) theoretical model for diabetes care, which points to important personal characteristics and other aspects that influence the outcome of care and the interaction between the patient and the health care professional. The patient’s and the health professional’s age, gender, body and psychosocial maturity as well as their global orientation and resistance resources, social support and previous

experiences of care are considered to be important aspects that affect the outcome of care and therefore would be of interest for the health professional's attention. Furthermore, the model demonstrates other aspects that are important for the outcome of the interaction and the disease management. These include the patient's and the nurse's understanding of illness, knowledge and learning and also their priorities and strategies which affect the interaction and outcome of care. If the interaction is meaningful and effective it will affect the outcome through improved metabolic control, fewer complications and increased well-being, which are international goals for effective diabetes care (WHO, 2002). Lundman's (1990) theoretical model was briefly discussed in the Background section, since my research was based on it. The model has been revised and the current version is presented as Figure 6.

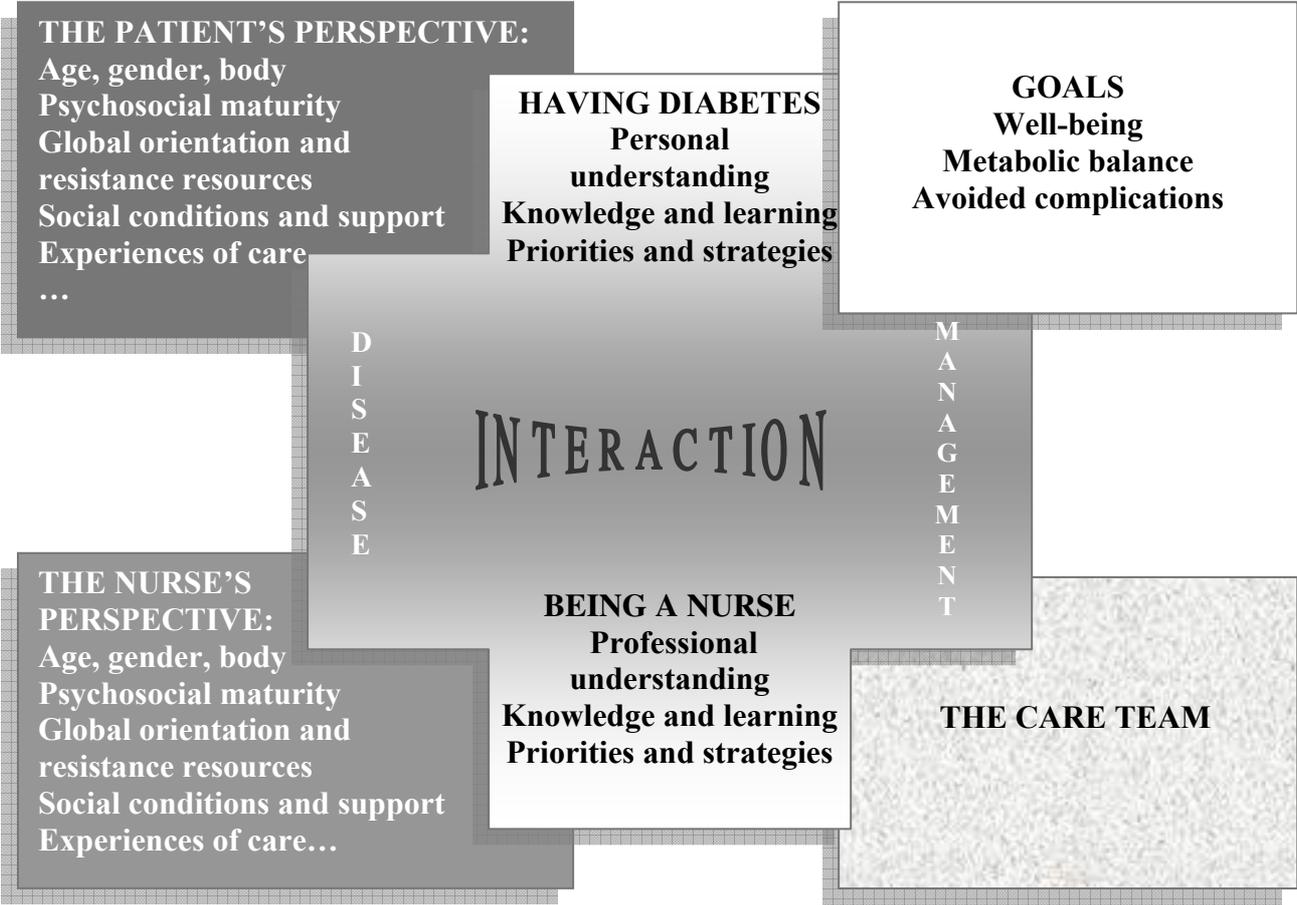


Figure 6. A revised theoretical model for diabetes care by Lundman, Norberg and Hörnsten

Some parts of the model have already been proved to be correct from much research accomplished, such as research on the influence of patients' age, gender and body, global orientation and resistance resources, social support,

coping strategies and learning as well as various aspects of interaction on the outcome (Glasgow et al, 1997; Sarkadi & Rosenquist, 2002; Drury & Louis, 2002; Agardh et al, 2003; Woolridge et al, 1992; Ross, 1991; Murry et al, 2001; Lundman & Norberg, 1993; Ellison and Rayman, 1998; Price, 1993; Anderson et al, 2003). Other parts have been elucidated within this thesis, including psychosocial maturity (Paper II), experiences of care (Papers III and IV), personal understanding of illness (Paper I) and also, aspects of the interaction between the nurse and the patient (Paper V). The remaining parts need to be further investigated and more aspects need to be added to the model. For example, the professional's prerequisites such as resistance resources and psychosocial maturity, as related to the outcome of care, would be an interesting area for future research. Furthermore, professionals' personal understanding of illness, and particularly the understanding of illness among professionals stricken by illness, would be of interest for research. The interaction needs further attention and it would be interesting to study "successful" caregivers whose patients are both satisfied and have satisfying metabolic balance. On the other hand, it would be interesting to compare differences between "successful" professionals whose patients are both satisfied and have satisfying metabolic balance as well as those not. The effect of the care team surrounding both the patient and the nurse is another important area for further research.

Besides a need for research to clarify the theoretical model for diabetes care, it is important for us to continue with annual follow-ups of the patients of the intervention study, in order to evaluate effects in the longer term. Moreover, with regard to education for health professionals it is important to introduce the various health and illness perspectives between patients and professionals at an early stage and further, to adapt student literature to this aim. The cost of the intervention is moderate and we believe it is possible to clinically implement this intervention within existing resources for primary health care.

Conclusion

The main findings of this thesis are that –

- patients' personal understanding of illness is an important source of self-management support for patients and care planning;
- using patients' personal understanding of illness as a basis for discussions in patient group sessions have positive effects on their metabolic balance and treatment satisfaction;
- nurses have difficulties integrating the different demands deriving from illness and disease perspectives in their work; furthermore, their views of their work do not always correspond with the patients' preferences for clinical encounters.
- lastly, patients' narratives about their lives may influence factors such as their self-management, since they include information about views on knowledge, capacity, motivation and courage.

SUMMARY IN SWEDISH – SVENSK SAMMANFATTNING

För att kunna ge en god omvårdnad vid diabetes är det viktigt att sjukvårdaren försöker ta del av patientens personliga förståelse av att leva med sjukdomen. Denna förståelse kan skilja sig från den professionella förståelsen av sjukdomen. Patienters syn på hälsa och sjukdom, kontroll, behandling och bot har samband med huruvida livsstilsförändringar vidtas och övrig behandling följs. Berättelser om sjukdomsupplevelser kan användas för att förstå vad människor anser är mest centralt i livssituationen och för egenvården.

Det övergripande syftet med avhandlingen var att studera erfarenheter av diabetes och diabetesvård bland personer med typ 2 diabetes och även bland sjuksköterskor ansvariga för diabetesvård, främst inom primärvården. Fyrtiofyra patienter, diagnostiserade med typ 2 diabetes under de senaste två åren, intervjuades om den personliga förståelsen av sjukdomen samt erfarenheter av sjukvård. De deltog också i en interventionsstudie bestående av gruppträffar under nio månader. Interventionen fokuserade på patienternas förståelse av att leva med diabetes och riktades till 44 patienter och fem sjuksköterskor ansvariga för deras vård.

Utfallsvariablerna haemoglobin A_{1c} (HbA_{1c}), blodfetter, blodtryck och kroppsmasseindex (BMI) samt välbefinnande, behandlingstillfredsställelse och upplevda diabetessymtom jämfördes mellan en interventions- och en kontrollgrupp. Ytterligare tio personer intervjuades om deras syn på sina liv. Sjutton sjuksköterskor intervjuades i fokusgrupper om synen på sitt arbete i diabetesvård. De enskilda intervjuerna och fokusgruppsintervjuerna analyserades med kvalitativ innehållsanalys.

Resultaten visade att patienternas personliga förståelse av att leva med diabetes handlade om ”bilden man har av sjukdomen, innebörden i diagnosen, integrationen av sjukdomen, utrymmet för sjukdomen, ansvar för sjukdomen samt framtidsprospekt”. Patienternas livsberättelser inkluderade deras syn på egen kunskap, kapacitet, motivation och eget mod, som kan anses vara viktiga aspekter för att lyckas med egenvården. Patienternas berättelser och reflektioner kring möten i vården tematiserades som tillfredsställande och icke tillfredsställande möten och handlade om att vara överens med vårdaren om målen eller ej, att vara självbestämmande och jämställd eller tvingad till anpassning och underkastelse, att känna sig värdefull som person eller värdelös, att bli uppmärksam och välkomnad eller att bli ignorerad samt slutligen att känna sig trygg och säker eller ej. Resultatet av interventionsstudien med gruppträffar ledde till förbättrad metabol balans och behandlingstillfredsställelse

i interventionsgruppen. Vid ettårsuppföljningen var skillnaden i HbA_{1c} i medeltal 0.94% (CI 0.58-1.29) mellan grupperna.

Sjuksköterskornas syn på sitt arbete innehöll teman som handlade om svårigheterna att integrera omvårdnadsperspektivet och behandlingsperspektivet, att de betraktade sina professionella kunskaper som viktigare än patienternas kunskaper, att de fick dåligt samvete av en del beslut de tog, att synen på den enskilde patienten ofta hamnade i skymundan av ett grupptänkande samt slutligen att sjuksköterskorna bekräftades i sin yrkesroll av de patienter som antog en traditionell patientroll.

Sammanfattningsvis visar dessa resultat på att förståelsen av sjukdom och synen på vård vid diabetes skiljer sig mellan patienter och sjuksköterskor i diabetesvård, ytterligare att en intervention som involverar både patienter och sjuksköterskor och som baseras på patienternas personliga förståelse av att leva med diabetes är effektiv avseende metabol kontroll och behandlingstillfredsställelse. Insatserna vid genomförandet av interventionen var måttliga och vi tror att den är möjlig att implementera i primärvårdens diabetesvård inom befintliga resurser.

ACKNOWLEDGEMENTS

The studies within this thesis were supported by grants from the Swedish Diabetes Association, the County Council of Västerbotten and the Elsa and Folke Sahlberg's foundation, and were carried out at the Department of Nursing and the Department of Public Health and Clinical Medicine at Umeå University, Umeå, Sweden. I am proud when I tell colleagues from other universities that I studied for my PhD at Umeå. I am particularly happy to have been a member of the seminar group consisting of PhD students, senior lecturers and professors from the Department of Nursing. Their support and criticism have been very constructive to my professional development and to the perspective I have developed as a scientist. They were among a number of people who guided me through these years and I would like to express my sincere gratitude especially to the following:

First of all, the nurses and patients who collaborated in the studies and shared thoughts as well as laboratory results with me. Your participation was most important for the development of this thesis. I want to thank you all very much.

Associate Professor Berit Lundman, my chief supervisor who introduced me to the "diabetes project" and trained me in qualitative as well as quantitative methods. You have given me excellent educational guidance, and I appreciate the confidence you had in my ability, which was often more than I had myself.

Assistant Professor Herbert Sandström, my second supervisor who particularly supported me in quantitative and medical questions raised during the realization and writing of the projects, but who also showed a great interest in qualitative methods. I would also like to thank you for "keeping cool" during some "overheated" discussions in the research group.

Professor Astrid Norberg, Head of the Department of Nursing of Umeå University, for encouraging and constructive advice, particularly in the initial phase of my PhD education; also, for intelligent and thoughtful comments during all our PhD seminars. Thank you for your refined humour; it really helped me gain sufficient distance to a problem to solve it.

Professor P-O Sandman, for constructive criticism as well as encouraging support, particularly in the last phase of my PhD education.

Ms Inga-Greta Nilsson, Institutional Secretary at the Department of Nursing, Ms Anita Sjöberg, Secretary (retired), and Ms Ann-Christine Edlund, for listening to

my complaints during the periods when I was down, but also, for a lot of laughter and for sharing lovely stories about your children and grandchildren.

The staff at the Department of Nursing, for many a pleasant and friendly talk. Special thanks go to the PhD students, and particularly my friend and colleague Ulla H Graneheim, who was always open to discussions about problems as well as about happiness in everyday life. Furthermore, I want to express my special thanks to my colleague and friend Birgitta Wiitavaara, to Lisbeth Sjöström and Anna-Lena Wennberg, for emotional support, and also, to my former roommates Regina Santamäki Fischer and David Edvardsson, for good friendship during years of hard work.

My former Masters students Agneta Almberg and Eva Kihl Sehlstam, who participated in the analysis of one paper each as part of their Master of Science work.

Our children. Firstly, my husband's lovely daughters Hanna and Maja, who supported me emotionally and also helped me with cooking and household work when I was travelling and attending conferences during the last years. Our lovely boys Carl, Johan and Fredrik, who were deprived of support from their mother in their schoolwork and other activities during the last few years, although they succeeded by themselves, so maybe they should thank me instead.

Finally, my husband Per, who always believed in my ability and pushed me, despite a lot of problems related to hard work and periods of separation due to our working situation. Our family has generally been under great pressure, particularly during the last few months, which was exacerbated by the accident you were involved in. I am happy that you are alive and are able to celebrate this day with me.

REFERENCES

- Adler AI, Stratton IM, Neil HA, Yudkin JS, Matthews DR, Cull CA, Wright AD, Turner RC, Holman RR. (2000) Association of systolic blood pressure with macrovascular and microvascular complications of type 2 diabetes (UKPDS 36): prospective observational study. *BMJ* 321, 412-418.
- Agardh CD, Berne C, Östman J. (2002) *Diabetes*. [Swe] Liber AB, Stockholm.
- Agardh EE, Ahlbom A, Andersson T, Efendic S, Grill V, Hallqvist J, Norman A, Östenson C. (2003) Work stress and low sense of coherence is associated with type 2 diabetes in middle-aged Swedish women. *Diabetes Care* 26, 719-724.
- Alberti KG, Gries FA. (1988) Management of non-insulin-dependent diabetes mellitus in Europe: a consensus view. *Diabetic Medicine* 5, 275-281.
- Allan JD. (1998) Explanatory models of overweight among African-American, Euro-American, and Mexican-American women. *Western Journal of Nursing Research* 20, 45-66.
- Alley GR, Brown LB. (2002) A diabetes problem solving support group: issues, process and preliminary outcomes. *Social Work in Health* 36, 1-9.
- Anderson RM, Funnell MM. (2000) Compliance and adherence are dysfunctional concepts in diabetes care. *The Diabetes Educator* 26, 579-604.
- Anderson RM, Funnell MM, Barr PA, Dedrick RF, Davis WK. (1991) Learning to empower patients: results of a professional education program for diabetes educators. *Diabetes Care* 14, 584-590.
- Anderson RM, Funnell MM, Butler PM, Arnold MS, Fitzgerald JT, Feste CC. (1995) Patient Empowerment: Results of a Randomized Control Trial. *Diabetes Care* 18, 943-949.
- Anderson RT, Balkrishnan R, Camacho F, Bell R, Duren-Winfield V, Goff D. (2003) Patient-centered outcomes of diabetes self-care. Associations with satisfaction and general health in a community clinic setting. *North Carolina Medical Journals* 64, 58-65.
- Andersson D. (1994) Diabetes Mellitus in defined population. A longitudinal study with special reference to early diagnosis, occurrence and mortality. *Medical Dissertation: Department of Family Medicine, University Hospital Uppsala*.
- Andersson S-O. (1995) Time and general practice consultations – aspects of length, attendance and quality. Umeå University Medical Dissertations, New Series 442, Sweden.
- Andersson Å. (2002) *Ett högt och ädelt kall: Kalltankens betydelse för sjuksköterskeyrkets formering 1850-1930*. [A high and noble calling: the notion of a calling and the formation of the nursing profession. Swe] PhD-thesis, Department of Historical studies, No 1. Umeå University, Umeå.
- Antonovsky A. (1987) *Unraveling the mystery of health*. Jossey-Bass Inc. Publishers, San Francisco.
- Antonovsky A. (1993) The structure and properties of the Sense of Coherence Scale. *Social Science and Medicine* 36, 725-733.
- Arborelius E. (1996) *Varför gör dom inte som vi säger?* [Why do they not do as we say?] Allmänmedicinskt utvecklingscentrum, Stockholm, Sweden.
- Armstrong D. (1986) The problem of the whole person in holistic medicine. *Holistic Medicine* 1, 27-36.
- Atkinson P. (1995) *Medical talk and medical work: The liturgy of the clinic*. Sage, Thousand Oaks, California.
- Barry CA, Bradley CP, Britten N, Stevenson FA, Barber N. (2000) Patients' unvoiced agendas in general practice consultations: qualitative study. *BMJ* 320,1246-1250.

- Barry CA, Stevenson F, Britten N, Barber N, Bradley C. (2001) Giving voice to the lifeworld. More humane, more effective medical care? A qualitative study of doctor-patient communication in general practice. *Social Science and Medicine* 53, 487-505.
- Baxter LA. (1991) Content analysis. In Montgomery BM, Duck S (eds.) *Studying interpersonal interaction*. (pp. 239-254). The Guilford Press, London, New York.
- Bradley C. (1994a) The wellbeing questionnaire. In Bradley C (ed.) *Handbook of psychology and diabetes*. (pp. 89- 109). Harwood Academic Publishers, Sydney, Australia.
- Bradley C. (1994b) Diabetes treatment satisfaction questionnaire (DTSQ). In Bradley C (ed.), *Handbook of psychology and diabetes*. (pp. 111- 131). Harwood Academic Publishers, Sydney, Australia.
- Bradley C, Lewis KS. (1990) Measures of psychological well-being and treatment satisfaction developed from the responses of people with tablet-treated diabetes. *Diabetic Medicine* 7, 445-451.
- Briant S, Freshwater D. (1998) Mental health nursing. Exploring mutuality within the nurse-patient relationship. *British Journal of Nursing* 7, 204-206, 208-211.
- Brown SA. (1999) Interventions to promote diabetes self-management: state of the science. *The Diabetes Educator* 25, 52-61.
- Bury M. (1991) The sociology of chronic illness: a review of research and prospects. *Sociology of Health and Illness* 13, 451-468.
- Bury M. (2001) Illness narratives: fact or fiction? *Sociology of Health and Illness* 23, 263-285.
- Cahill J. (1998) Patient participation - a review of the literature. *Journal of Clinical Nursing* 7, 119-128.
- Carlsson A, Rosenqvist U. (1991) Diabetes care organization, process, and patient outcomes: effects of a diabetes control program. *The Diabetes Educator* 17, 42-48.
- Cassell EJ. (1976) Disease as in 'it': concepts of disease revealed by patients' presentation of symptoms. *Social Science and Medicine* 10, 143-146.
- Charles C, Gafni A, Whelan T. (1997) Shared decision-making: what does it mean? (or it takes at least two to tango). *Social Science and Medicine* 44, 681-692.
- Charles C, Whelan T, Gafni A. (1999) What do we mean by partnership in making decisions about treatment? *BMJ* 319, 780-782.
- Charmaz K. (1993) *Good Days, Bad Days: The Self in Chronic Illness and Time*. Rutgers University Press, New Brunswick.
- Chesla CA, Skaff MM, Bartz RJ, Mullan JT, Fisher L. (2000) Differences in personal models among Latinos and European Americans: implications for clinical care. *Diabetes Care* 23, 1780-1785.
- Coates VE, Boore JR. (1996) Knowledge and diabetes self-management. *Patient Education and Counseling* 29, 99-108.
- Cohen MZ, Tripp-Reimer T, Smith C, Sorofman B, Lively S. (1994) Explanatory models of diabetes: patient practitioner variation. *Social Science and Medicine* 38, 59-66.
- Conrad P. (1987) The experience of illness: recent and new directions. *Research in the Sociology of Health Care* 6, 1-31.
- Conrad P, Bury M. (1997) Anselm Strauss and the sociological study of chronic illness: a reflection and appreciation. *Sociology of Health and Illness* 19, 373-376.
- Coyle J, Williams B. (2001) Valuing people as individuals: development of an instrument through a survey of person-centredness in secondary care. *Journal of Advanced Nursing* 36, 450-459.
- DCCT 36. (1995) No authors listed. Progression of retinopathy with intensive versus conventional treatment in the Diabetes Control and Complication Trial. Diabetes Control and Complications Trial Research Group. *Ophthalmology* 102, 647-661.

- Downe-Wamboldt B. (1992) Content analysis: method, applications, and issues. *Health Care for Women International* 13, 313-321.
- Drury CA, Louis M. (2002) Exploring the association between body weight, stigma of obesity, and health care avoidance. *Journal of the American Academy of Nurse Practitioners* 14, 554-561.
- Eisenberg L. (1977) Disease and illness: distinctions between professional and popular ideas of sickness. *Culture, Medicine and Psychiatry* 1, 9-23.
- Ellis SE, Speroff T, Dittus RS, Brown A, Pichert JW, Elasy TA. (2004) Diabetes patient education: a meta-analysis and meta-regression. *Patient Education and Counseling* 52, 97-105.
- Ellison GC, Rayman KM. (1998) Exemplars' experience of self-managing type 2 diabetes. *The Diabetes Educator* 24, 325-330.
- Erikson EH, Erikson JM. (1997) *The Life Cycle Completed*. W. W. Norton: New York.
- Expert Committee. (1997) Report of the Expert Committee on the diagnosis and classification of diabetes mellitus. *Diabetes Care* 20, 1183-1197.
- Fabrega H. Jr. (1974) Problems implicit in the cultural and social study of depression. *Psychosomatic Medicine* 36, 377-98.
- Falkenberg M. (1990) Metabolic control and amputations among diabetics in primary health care – a population based intensified programme governed by patient education. *Scandinavian Journal of Primary Health Care* 8, 25-29.
- Francioni FF, Silva DMG. (2002) The acceptance process in living with diabetes mellitus: considerations on the environment's influence [In Portuguese]. *Texto Contexto Enfermagem*. 11, 36-43.
- Frank A. (1997) Illness as moral occasion: restoring agency to ill people. *Health* 1, 131-148.
- Frank AW. (1998) Just listening: narrative and deep illness. *Families, Systems & Health: The Journal of Collaborative Family HealthCare* 6, 197-212.
- Freidson E. (1970) *Profession of medicine: a study in the sociology of applied knowledge*. University of Chicago Press, Chicago.
- Gafaranga J, Britten N. (2003) "Fire away": the opening sequence in general practice consultations. *Family Practice* 20, 242-247.
- Gilden JL, Hendryx M, Casia C, Singh SP. (1989) The effectiveness of diabetes education programs for older patients and their spouses. *Journal of the American Geriatrics Society* 11, 1023-1030.
- Gilden JL, Hendryx MS, Clar S, Casia C, Singh SP. (1992) Diabetes support groups improve health care of older diabetic patients. *Journal of the American Geriatrics Society* 40, 147-150.
- Glasgow RE, Hampson SE, Strycker LA, Ruggiero L. (1997) Personal-model beliefs and social-environmental barriers related to diabetes self-management. *Diabetes Care* 20, 556-561.
- Goedhuis J, Rethans JJ. (2001) On the relationship between the efficiency and the quality of consultation. A validity study. *Family Practice* 18, 592-596.
- Graber AL, Elasy TA, Quinn D, Wolff K, Brown A. (2002) Improving glycemic control in adults with diabetes mellitus: shared responsibility in primary care practices. *Southern Medical Journal* 95, 684-690.
- Graneheim UH, Lundman B. (2004) Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today* 24, 105-112.
- Gray A, Raikou M, McGuire A, Fenn P, Stevens R, Cull C, Stratton I, Adler A, Holman R, Turner R. (2000) Cost effectiveness of an intensive blood glucose control policy in

- patients with type 2 diabetes: economic analysis alongside randomised controlled trial. *BMJ* 320, 1373-1378.
- Griffin S. (1999) Improving education for type 2 diabetes patients in general practice. *Practical Diabetes International* 16, 235.
- Grol R, de Maeseneer J, Whitfield M, Mokka H. (1990) Disease-centred versus patient-centred attitudes: comparison of general practitioners in Belgium, Britain and The Netherlands. *Family Practice* 7, 100-103.
- Grootenhuis PA, Snoek FJ, Heine RJ, Bouter LM. (1994) Development of a type 2 diabetes symptom checklist: a measure of symptom severity. *Diabetic Medicine* 11, 253-261.
- Hagger MS, Orbell S. (2003) A meta analytic review of the common-sense model of illness representations. *Psychology and Health* 18, 141-184.
- Hahl J, Hämäläinen H, Sintonen H, Simell T, Arinen S, Simell O. (2002) Health-related quality of life in type 1 diabetes without or with symptoms of long-term complications. *Quality of Life Research* 11, 427-436.
- Hampson SE, Glasgow R, Toobert DJ. (1990) Personal models of diabetes and their relations to self-care activities. *Health Psychology* 9, 632-646.
- Hampson SE, Glasgow RE, Foster LS. (1995) Personal models of diabetes among older adults: relationship to self-management and other variables. *The Diabetes Educator* 21, 300-307.
- Henriksen E, Rosenqvist U. (2003) Understanding cardiac follow-up services – a qualitative study of patients, health care professionals, and managers. *European Journal of Cardiovascular Nursing* 2, 95-104.
- Hernandez CA. (1995) The experience of living with insulin-dependent diabetes: lessons for the diabetes educator. *Diabetes Educator* 21, 33-37.
- Hill J, Gilroy J. (2002) Using group education sessions to start patients on insulin. *Journal of Diabetes Nursing* 6, 104-108.
- Hjelm K, Nyberg P, Isacson A, Apelqvist J. (1999) Beliefs about health and illness essential for self-care practice: a comparison of migrant Yugoslavian and Swedish diabetic females. *Journal of Advanced Nursing* 30, 1147-1159.
- Hjelm K, Nyberg P, Apelqvist J. (2003) Religious and cultural distance in beliefs about health and illness in women with diabetes mellitus of different origin living in Sweden. *International Journal of Nursing Studies* 40, 627-643.
- Howgego IM, Yellowlees P, Owen C, Meldrum L, Dark F. (2003) The therapeutic alliance: the key to effective patient outcome? A descriptive review of the evidence in community mental health case management. *Australian and New Zealand Journal of Psychiatry* 37, 169-183.
- Hunt LM, Arar NH, Larme AC. (1998) Contrasting patient and practitioner perspectives in type 2 diabetes management- including commentary by Ratkin SH and Anderson RM with author response. *Western Journal of Nursing Research* 20, 656-682.
- Huttlinger K, Krefting L, Drevdahl D, Tree P, Baca E, Benally A. (1992) “Doing battle”: a metaphoric analysis of diabetes mellitus among Navajo People. *American Journal of Occupational Therapy* 46, 706-712.
- Hydén LC. (1997) Illness and narrative. *Sociology of Health and Illness* 19, 48-69.
- Jennings D. (1986) The confusion between disease and illness in clinical medicine. *Canadian Medical Association Journal* 135, 865-870.
- Karhila P, Kettunen T, Poskiparta M, Liimatainen L. (2003) Negotiation in type 2 diabetes counseling: from problem recognition to mutual acceptance during lifestyle counseling. *Qualitative Health Research* 13, 1205-1224.

- Keen H. (1996) Management of non-insulin-dependent diabetes mellitus. The United Kingdom experience. *Annual Internal Medicine* 124, 156-159.
- King EB, Schlundt DG, Pichert JW, Kinzer CK, Backer BA. (2002) Improving the skills of health professionals in engaging patients in diabetes-related problem solving. *Journal of Continuing Education in the HealthCare Professions* 22, 94-102.
- Kitzinger J. (1995) Qualitative research. Introducing focus groups. *BMJ*. 311, 299-302.
- Kivimäki M, Feldt T, Vahtera J, Nurmi J. (2000) Sense of coherence and health: evidence from two cross-lagged longitudinal samples. *Social Science and Medicine* 50, 583-597.
- Kleinman A. (1988) *The illness narratives: suffering, healing and the human condition*. Basic Books, Inc. New York.
- Koch T, Kralik D, Sonnack D. (1999) Women living with type two diabetes: the intrusion of illness. *Journal of Clinical Nursing* 8, 712-722.
- Koch T, Kralik D, Taylor J. (2000) Men living with diabetes: minimizing the intrusiveness of the disease. *Journal of Clinical Nursing* 9, 247-254.
- Kothari V, Stevens RJ, Adler AI, Stratton IM, Manley SE, Neil HA, Holman RR. (2002) UKPDS 60; risk of stroke in type 2 diabetes estimated by the UK Prospective Diabetes Study risk engine. *Stroke* 33, 1776-1781.
- Kvale S. (1997) *Den kvalitativa forskningsintervjun* [Interviews]. Studentlitteratur, Lund, Sweden.
- Laine C. (1997) Should physicians discourage patients from playing the sick role? *Canadian Medical Association Journal* 157, 393-394.
- Laine C, Davidoff F. (1996) Patient-centered medicine. A professional evolution. *The Journal of the American Medical Association* 275, 152-156.
- Langius A, Björvell H. (1993) Coping ability and functional status in a Swedish population sample. *Scandinavian Journal of Caring Sciences* 7, 3-10.
- Larme AC, Pugh JA. (1998) Attitudes of primary care providers toward diabetes: barriers to guideline implementation. *Diabetes Care* 21, 1391-1396.
- Lau RR, Hartman KA. (1983) Common sense representations of common illnesses. *Health Psychology* 2, 167-185.
- Lawrence C. (1994) *Medicine in the making of modern Britain 1700-1920*. Routledge, London.
- Levenstein J, McCracken E, McWhinney I, Stewart M, Brown J. (1986) The patient-centred clinical method 1: a model for the doctor-patient interaction in family medicine. *Family Practice* 3, 24-30.
- Leventhal H, Meyer D, Nerenz D. (1980) The common sense model of illness danger, in Rachman S (ed.) *Contributions to Medical psychology*. (pp. 7-30), Vol 2. Pergamon Press, New York.
- Lincoln YS, Guba EG. (1985) *Naturalistic inquiry*. Sage Publications Inc, Newsbury Park, London, New Delhi.
- Lindseth A, Norberg A. A phenomenological hermeneutical method for researching lived experience. (Accepted for publication) *Scandinavian Journal of Caring Sciences*.
- Linné Y, Barkeling B, Rössner S. (2002) Natural course of gestational diabetes mellitus: long term follow up of women in the SPAWN study. *An International Journal of Obstetrics and Gynaecology* 109, 1227-1231.
- Little P, Everitt H, Williamsin I, Warner G, Moore M, Gould C, Ferrier K, Payne S. (2001) Preferences of patients for patient centred approach to consultation in primary care: observational study. *BMJ* 322, 468-472.

- Loewe R, Freeman J. (2000) Interpreting diabetes mellitus: differences between patient and provider models of disease and their implications for clinical practice. *Culture, Medicine and Psychiatry* 24, 379-401.
- Lundman B. (1990) *Daily living and coping strategies in insulin-dependent diabetics diagnostic reasoning in nursing*. [Swe] Umeå University Medical Dissertations, New Series No 298, Umeå.
- Lundman B, Engström L. (1998) Diabetes and its complications in a Swedish county. *Diabetes Research and Clinical Practice* 39, 157-164.
- Lundman B, Norberg A. (1993) Coping strategies in people with insulin-dependent diabetes mellitus. *The Diabetes Educator* 19, 198-204.
- Lupton D. (1994) *Medicine as culture: illness, disease and the body in Western societies*, (p. 93) Sage Publishing, London.
- Luyas GT. (1991) An explanatory model of diabetes. *Western Journal of Nursing Research* 13, 681-693; discussion 695-697.
- Madden BP. (1990) The hybrid model for concept development: its value for the study of therapeutic alliance. *Advances in Nursing Science* 12, 75-87.
- Maroney D, Golub S. (1992) Nurses' attitudes toward obese persons and certain ethnic groups. *Perceptual and Motor Skills* 75, 387-391.
- Martin LR, DiMatteo MR, Lepper HS. (2001) Facilitation of patient involvement in care: development and validation of a scale. *Behavioral Medicine* 27, 111-120.
- McNabb WL, Ouinn MT, Rosing L. (1993) Weight loss program for inner-city black women with non-insulin-dependent diabetes mellitus: PATH-WAYS. *Journal of the American Dietetic Association* 93, 75-77.
- McSweeney JC, Allan JD, Mayo K. (1997) Theory. Exploring the use of explanatory models in nursing research and practice. *Image: Journal of Nursing Scholarship* 29, 243-248.
- McWhinney I. (1989) The need for a transformed clinical method. In Stewart M, Roter D (eds.) *Communicating with medical patients*. (pp. 25-42) Sage Publishing, Newbury Park, London.
- Mead N, Bower P. (2000) Patient-centredness: a conceptual framework and review of the empirical literature. *Social Science and Medicine* 51, 1087-1110.
- Michael SR. (1996) Integrating chronic illness into one's life- a phenomenological inquiry. *Journal of Holistic Nursing* 3, 251-267.
- Mishler EG. (1984) *The discourse of medicine: Dialectics of medical interviews*. (p. 104) Ablex Publishing Co, New Jersey.
- Mishler EG. (1986) *Research interviewing. Context and narrative*. Harvard University Press, Cambridge, Massachusetts.
- Mitcheson J, Cowley S. (2003) Empowerment or control? An analysis of the extent to which client participation is enabled during health visitor/client interactions using a structured health needs assessment tool. *International Journal of Nursing Studies* 40, 413-426.
- Morse JM. (1997) Responding to threats to integrity of self. *Advances in Nursing Science* 19, 21-36.
- Murry VM, Brown PA, Brody GH, Cutrona CE, Simons RL. (2001) Racial discrimination as a moderator of the links among stress, maternal psychological functioning, and family relationships. *Journal of Marriage and Family* 63, 915-926.
- National Diabetes Data Group. (1995) *Diabetes in America*. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, NIH publication no. 95-1468, 2d ed. Bethesda, Maryland.

- NHS Executive. (1996) *Patient partnership: building a collaborative strategy*. NHS Executive, Leeds.
- Nilsson I, Axelsson K, Gustafson Y, Lundman B, Norberg A. (2001) Well-being, sense of coherence, and burnout in stroke victims and spouses during the first few months after stroke. *Scandinavian Journal of Caring Sciences* 15, 203-214.
- Norris SL, Nichols PJ, Caspersen CJ, Glasgow RE, Engelgau MM, Jack L, Snyder SR, Carande-Kulis VG, Isham G, Garfield S, Briss P, McCulloch D. (2002) Increasing diabetes self-management education in community settings. A systematic review. *American Journal of Preventive Medicine* 22, 39-66.
- Nyhlin KT, Lithner F, Norberg A. (1987) Experience of being diabetic –“It is up to oneself to manage”. *Scandinavian Journal of Caring Sciences* 1, 59-62.
- Ogden J, Bandara I, Cohen H, Farmer D, Hardie J, Minas H, Moore J, Qureshi S, Walter F, Whitehead MA. (2001) General practitioners' and patients' models of obesity: whose problem is it? *Patient Education and Counseling* 44, 227-233.
- Ovhed I, Johansson E, Odeberg H, Råstam L. (2000) A comparison of two different team models for treatment of diabetes mellitus in primary care. *Scandinavian Journal of Caring Sciences* 14, 253-258.
- Parchman ML, Arambula-Solomon TG, Hitchcock Noël P, Larme AC, Pugh JA. (2003) Stage of change advancement for diabetes self-management behaviors and glucose control. *The Diabetes Educator* 29, 128-134.
- Parsons T. (1951) *The social system*, Glencoe Free Press, Glencoe, Illinois.
- Paterson B. (2001a) Myth of empowerment in chronic illness. *Journal of Advanced Nursing* 34, 574-581.
- Paterson, BL. (2001b) The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship* 1, 21-26.
- Paterson B, Sloan JA. (1994) A phenomenological study of the decision-making of individuals with long-standing diabetes. *The Canadian Journal of Diabetes Care* 18, 10-19.
- Paterson B, Thorne S, Crawford J, Tarko M. (1999) Living with diabetes as a transformational experience. *Qualitative Health Research* 9, 786-802.
- Paterson BL, Thorne S, Dewis M. (1998) Adapting to and managing diabetes. *Journal of Nursing Scholarship* 1, 57-62.
- Poss J, Jezewski MA. (2002) The role and meaning of susto in Mexican Americans' explanatory model of type 2 diabetes. *Medical Anthropology Quarterly* 16, 360-377.
- Price JH, Desmond SM, Krol RA, Snyder FF, O'Connell JK. (1987) Family practice physicians' beliefs, attitudes, and practices regarding obesity. *American Journal of Preventive Medicine* 3, 339-345.
- Price MJ. (1993) An experiential model of learning diabetes self-management. *Qualitative Health Research* 3, 29-54.
- Puhl R, Brownell KD. (2001) Bias, discrimination, and obesity. Review. *Obesity Research* 9, 788-805.
- Reach G. (2003) Observance in diabetes: from therapeutic education to therapeutic alliance. *Annales de Médecine Interne (Paris)* 154, 117-120.
- Renders CM, Valk GD, Griffin S, Wagner EH, Eijk JThM van, Assendelft WJJ. (2002) Interventions to improve the management of diabetes mellitus in primary care, outpatient and community settings (Cochrane Review) *Ugeskrift Laeger* 164, 607-609.
- Ross ME. (1991) Hardiness and compliance in elderly patients with diabetes. *The Diabetes Educator* 17, 372-375.

- Royal Pharmaceutical Society of Great Britain. (1997) *From compliance to concordance: Achieving shared goals in medicine taking*. RPSGB, London. Available at: <http://www.concordance.org> Accessed March 05, 2004.
- Rubin RR, Peyrot M. (1999) Quality of life and diabetes. *Diabetes Metabolism Research and Reviews* 15, 205-218.
- Saleh Stattin N. (2001) *Immigrant patients with diabetes: How they understand, learn to manage and live with their diabetes*. PhD-thesis, Uppsala Universitet, Uppsala, Sweden.
- Sandelowski M. (1991) Telling stories: Narrative approaches in qualitative research. *Image: Journal of Nursing Scholarship* 23, 161-166.
- Sandén-Eriksson B. (2000) Coping with type-2 diabetes: the role of sense of coherence compared with active management. *Journal of Advanced Nursing* 31, 1393-1397.
- Sarkadi A, Rosenqvist U. (2002) Social network and role demands in women's Type 2 diabetes: a model. *Health Care Women International* 23, 600-611.
- Scott RS, Beaven DW, Stafford JM. (1984) The effectiveness of diabetes education for non-insulin-dependent diabetic persons. *The Diabetes Educator* 10, 36-39.
- Socialstyrelsen [The Swedish National Board of Health and Welfare. Swe]. (1999) Nationella riktlinjer för vård och behandling vid diabetes mellitus - Version för hälso- och sjukvårdspersonal [National guidelines for care and treatment in diabetes mellitus – version for health care professionals] Available at: <http://www.sos.se> Accessed March 05, 2004.
- Socialstyrelsen [The Swedish National Board of Health and Welfare. Swe]. (2001) Folkhälsorapport 2001– Kapitel 3. [Public Health Report 2001 – Chapter 3.]. Available at: <http://www.sos.se> Accessed March 05, 2004.
- Steed L, Cooke D, Newman S. (2003) A systematic review of psychosocial outcomes following education, self-management and psychological interventions in diabetes mellitus. *Patient Education and Counseling* 51, 5-15.
- Stensland P, Malterud K. (2001) Unravelling empowering internal voices—a case study on the interactive use of illness diaries. *Family Practice* 18, 425-429.
- Stewart MA. (1995) Effective physician-patient communication and health outcomes: a review. *Canadian Medical Association Journal* 152, 1423-1433.
- Stewart MA, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, Jordan J. (2000) The impact of patient-centred care on outcomes. *Journal of Family Practice* 49, 796-804.
- Stivers T. (2002) Participating in decisions about treatment: overt parent pressure for antibiotic medication in pediatric encounters. *Social Science and Medicine* 54, 1111-1130.
- Stratton IM, Adler AI, Neil HA, Matthews DR, Manley SE, Cull CA, Hadden D, Turner RC, Holman RR. (2000) Association of glycemia with macrovascular and microvascular complications of type 2 diabetes (UKPDS 35): prospective observational study. U.K. Prospective Diabetes Study Group. *BMJ* 321, 405-412.
- Surtees P, Wainwright N, Luben R, Khaw KT, Day N. (2003) Sense of coherence and mortality in men and women in the EPIC-Norfolk United Kingdom prospective cohort study. *American Journal of Epidemiology* 158, 1202-1209.
- Tattersall RB, McCulloch DK, Aveline M. (1985) Group therapy in the treatment of diabetes. *Diabetes Care* 8, 180-188.
- Toombs K. (1993) *The meaning of illness. A phenomenological account of the different perspective of physicians and patients*. Kluwer Academic Publishers, London.
- Toombs SK. (1995) Chronic illness and the goals of medicine. *Second Opinion* 21, 11-19.

- UKPDS (1998) No authors listed. Intensive blood-glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type 2 diabetes. (UKPDS 33) U.K. Prospective Diabetes Study Group. *Lancet* 352, 837-853.
- UKPDS (1999) No authors listed. Quality of life in type 2 diabetic patients is affected by complications but not by intensive policies to improve blood glucose or blood pressure control. (UKPDS 37) U.K. Prospective Diabetes Study Group. *Diabetes Care* 22, 1125-1136.
- Van der Does FE, De Neeling JN, Snoek FJ, Kostense PJ, Grootenhuys PA, Bouter LM, Heine RJ. (1996) Symptoms and well-being in relation to glycaemic control in type II diabetes. *Diabetes Care* 19, 204-210.
- Weinberger M, Kirkman MS, Samsa GP, Shortliffe EA, Landsman PB, Cowper PA, Simel DL, Feussner JR. (1995) A nurse-coordinated intervention for primary care patients with non-insulin-dependent diabetes mellitus: impact on glycaemic control and health-related quality of life. *Journal of General Internal Medicine* 10, 59-66.
- Whittemore R, Chase S, Mandle CL, Roy SC. (2001) The content, integrity and efficacy of a nurse coaching intervention in type 2 diabetes. *The Diabetes Educator* 27, 887-898.
- Woolridge KL, Wallston KA, Graber AL, Brown AW, Davidson P. (1992) The relationship between Health Beliefs, adherence and metabolic control of diabetes. *The Diabetes Educator*, 18, 495-500.
- World Health Organization (WHO) (2002) *Fact sheet no 138* Available at: <http://www.who.int/inf-fs/en/fact138.html> Accessed March 05, 2004.
- World Health Organization (WHO) Europe and International Diabetes Federation (IDF) Europe (1995), The Acropolis Affirmation. *Diabetes Care - St Vincent in progress, Diabetic Medicine* 12, 636.
- Zauszniewski JA, McDonald PE, Krafcik K, Chung C. (2002) Acceptance, cognitions, and resourcefulness in women with diabetes. *Western Journal of Nursing Research*, 24, 728-750.
- Zola IK. (1973) Pathways to the doctor- from person to patient. *Social Science and Medicine* 7, 677-689.