Patient Education for People with Type 2 Diabetes in Primary Health Care

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Dissertation presented at Uppsala University to be publicly examined in Samlingssalen, Psykiatriccentrum, Centrallasaretet, Ing 29, Västerås, Friday, September 26, 2008 at 13:15 for the degree of Doctor of Philosophy (Faculty of Medicine). The examination will be conducted in Swedish.

Abstract


The general aim of this thesis was to evaluate different aspects of patient education for people with type 2 diabetes in Swedish primary health care.

The evaluation was conducted in a primary health care setting in central Sweden and in Swedish primary health care in its entirety. Seven centres in central Sweden had implemented the empowerment programme for patients with type 2 diabetes. Data on 16 care providers’ views on implementing the programme were collected in focus-group interviews. The effect and the patients’ experiences of the programme were evaluated in a randomized controlled trial (RCT) (n=101) and in individual interviews (n=28). In the RCT, 50 patients were assigned to the programme and 51 patients to routine diabetes care. The patients answered a 27-item questionnaire and BMI and HbA1c were measured, before the intervention and at one-year follow-up. Further, data from 485 primary health care centres with 91,637 diabetic patients were collected to evaluate patient education in Swedish primary health care in its entirety.

The care providers experienced conflicting roles in changing from expert to facilitator in the empowerment programme. The programme improved patients’ confidence in diabetes knowledge and contributed to their experience of self-control, while patients in the routine diabetes care experienced external control. Of the 485 centres, 50% reported having checklist-driven individual counselling and 8% that they individualized the counselling based upon patients’ needs. Most centres (>90%) set individual goals, but only one-third involved patients in the final decisions regarding their goals. Setting individual goals was found to have an impact on patients’ possibilities to reach national treatment targets.

In conclusion, the implementation of empowerment in patient education demands support to care providers in order to influence patients’ self-care. Furthermore, patients need to reflect upon necessary self-care changes and also set individual goals to facilitate the reaching of national treatment targets.

Keywords: Diabetes mellitus, empowerment, patient education, primary health care

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ISSN 1651-6206
urn:nbn:se:uu:diva-9200 (http://urn.kb.se/resolve?urn=urn:nbn:se:uu:diva-9200)
In memory of my first mentor late Anita Carlson, who introduced empowerment in Swedish diabetes care; thinking of you empowers me!
List of Papers

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


IV Adolfsson ET, Smide B, Rosenblad A, Wikblad K. Does patient education facilitate diabetic patients’ possibilities to reach national treatment targets? – A national survey in Swedish primary health care (Submitted)

The papers have been printed with permission from the respective publisher.
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Abbreviations

ACCORD  Action to Control Cardiovascular Risk in Diabetes
BMI     Body Mass Index
CAD     Coronary Artery Disease
CVD     Cardiovascular Disease
DSN     Diabetes Specialist Nurse
EASD    European Association for the Study of Diabetes
ESC     European Society of Cardiology
GP      General Practitioner
HbA$_{1c}$ Haemoglobin A$_{1c}$
ITT     Intention-to-treat
LUCD    Diabetes Education and Research Centre
MDRTC   Michigan Diabetes Research and Training Center
NDR     National Diabetes Register
OHA     Oral Hypoglycaemic Agent
QOF     Quality and Outcome Framework
RCT     Randomized Controlled Trial
SFD     Swedish Association of Diabetology
UKPDS   United Kingdom Prospective Diabetes Study
VAS     Visual Analogue Scale

All abbreviations used in this thesis except those used only once are listed here.
Gunnar is 63 years old. Ten years ago, high blood glucose levels were detected at a general health check-up at his primary health care centre; his sensitivity to insulin had declined. He was diagnosed with type 2 diabetes. Gunnar realized afterwards that he had probably had the disease long before it was diagnosed. For a long time he had felt thirsty and had frequent passing of urine. His father had been diagnosed with the disease at around 70 years of age. Gunnar had expected to be affected by the disease, because he knew that type 2 diabetes was strongly hereditary.

First of all, Gunnar had to start treating the disease by changing his diet in order to lose weight. His general practitioner (GP) gave him general information about the disease. The diabetes specialist nurse (DSN) talked about self-care and gave him advice about food intake, and recommended that he should exercise regularly. It was also recommended that he takes annual contact with his GP and DSN for medical check-ups and individual counseling. Gunnar followed their advice and visited his GP and DSN annually. He appreciated their having control over his disease.

After some years, Gunnar received supplementary treatment in the form of oral hypoglycaemic agents (OHA). After another year his GP also suggested supplementation with insulin, because his level of insulin secretion had decreased. Gunnar was not at all satisfied with the GP’s suggestion, wanting to continue to treat his diabetes with diet, exercise and OHA. His GP proposed that he should participate in the hospital’s one-week education programme for patients with type 2 diabetes to consider the suggested insulin treatment and to have the possibility to learn more about his disease. Gunnar was thus referred to the hospital’s one-week programme.

At that time I was working as dietician on the diabetes team at the Västerås Central Hospital. I met Gunnar when he participated in our one-week programme for patients with type 2 diabetes. I interviewed 11 of the patients who participated in the programme and Gunnar was one of them. The data from these interviews gave me the insight that people with type 2 diabetes need to be provided with patient education in diabetes at an earlier stage of their disease. This experience was the origin of this thesis.
Introduction

Type 2 diabetes
In Sweden, 2.2-4.5% of the population (around 350,000 people) suffer from diabetes mellitus (1-4). Type 2 diabetes accounting for 85-90% and type 1 diabetes the other 10-15% (5). More than one and a half million people, or 20% of the Swedish population, are considered to be predisposed to developing type 2 diabetes (6). The prevalence of type 2 diabetes increases with increasing age, and affects about 8-10% in the age group over 75 years. It is not only age that influences the onset of diabetes; obesity (7-10) inactivity (7, 11), smoking (12-14) and stress (15, 16) have also been found to play an important role in the development of the condition. The hereditary component is not unimportant (10, 17) and different factors in the environment also have an impact on the condition (7-16).

Type 2 diabetes implies that blood glucose levels increase as a consequence of decreased insulin secretion and/or decreased insulin sensitivity (insulin resistance) (18). Type 2 diabetes is a progressive disease, and the progressive nature of the condition requires continual augmentation of the treatment (19-21).

Care for people with type 2 diabetes
Main components in the care for people with type 2 diabetes are medical treatment and patient education and counselling. Education is important, since most of the time the person with diabetes must make self-care decisions and to be able to do this he/she needs knowledge. In Sweden, like in many other countries, diabetes care and education for people with type 2 diabetes are organized at primary health care centres (22-25). These centres are responsible for a defined population, or for a certain number of listed patients. The GPs at the centres are general specialists in public health. Most of the centres also have a GP responsible for diabetes care as well as one or more DSNs. Patients with type 2 diabetes generally visit their GP and their DSN at least once a year (26). The patients receive individual counselling and recommendations based on the results of biochemical tests and examinations they undergo at these visits. They also receive new prescriptions for their medications and test strips for their blood-glucose monitoring.
centres may also offer group education programmes as a complement to the individual counselling.

The care providers at the centres co-operate in order to offer good care for the individual patient (27). In general, the diabetes team at the centre includes the patient, a GP and one or more DSNs. Large centres might have other care providers on the team, such as dieticians, podiatrists, physiotherapists, psychologists and/or social workers. If these professionals are unavailable at the centres the patients can be referred to them elsewhere.

Treatment and self-care in people with type 2 diabetes

Most patients’ first treatment option is a healthy diet and increased physical activity. OHA is usually not needed until dietary treatment has failed. When insulin secretion is too low, supplementation with insulin is required. Insulin treatment is often needed within ten years after diagnosis (21). Most people with type 2 diabetes are overweight and have different components of the metabolic syndrome. This syndrome has varied in its definition, but its main components are impaired glucose regulation or diabetes, insulin resistance, central obesity, impact on lipid levels, raised blood pressure, and microalbuminuria (28, 29). Each of these components increases the risk of being affected by micro- and macrovascular complications (30).

Type 2 diabetes is a progressive disease (19-21). However, people with type 2 diabetes can influence its progression and prevent complications by maintaining or trying to reach near-normal levels of haemoglobin A1c (HbA1c), blood pressure, blood lipids and Body Mass Index (BMI), and by performing regular physical activity (31-35). For the individual this means self-monitoring of blood glucose, adjusting medication, choosing healthy food, trying to lose weight and performing regular exercise (36). Patient education in diabetes is provided for people with type 2 diabetes to enable them to understand their condition and how to manage it in their daily life (37).

National guidelines and treatment targets

In general, diabetes care and education at the centres is based on the county council’s or the region’s local guidelines, which are based on the Swedish national guidelines for care and treatment in diabetes. The first guidelines from the Swedish National Board of Health and Welfare were established in 1996 (38). The background of these first guidelines was the 1989 St. Vincent declaration in Italy, an agreement between European countries to “plan for prevention, identification and treatment of diabetes and particularly its complications.” The guidelines “should be formulated at local, national and European regional level” (39, p. 360).
As mentioned above, in Sweden diabetes care and education is to be based on the Swedish national guidelines for care and treatment in diabetes. In 1999 a revised edition of these national guidelines was published (40). In 2006/2007 the Swedish Association of Diabetology (SFD) presented a proposal for national treatment targets in diabetes (41) in line with treatment targets from the European Society of Cardiology (ESC) and the European Association for the Study of Diabetes (EASD) (33) (Table I). In 2009, new evidence-based guidelines are expected.

The overall aim of the treatment targets is to prevent acute complications and long-term micro- and macrovascular complications (33); long-term complications are reported to decrease patients’ wellbeing and quality of life (42). According to the St. Vincent declaration, the general goals for people with diabetes are: “Sustained improvement in health experience and a life approaching normal expectation in quality and quantity” (39, p. 360).

Table I. Treatment targets for people with type 2 diabetes.

<table>
<thead>
<tr>
<th>Treatment targets</th>
<th>SNG 1999</th>
<th>SFD 2006-2007</th>
<th>ESC-EASD 2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>HbA1c (%)</td>
<td>&lt; 6.5</td>
<td>5-6</td>
<td>≤ 5.5</td>
</tr>
<tr>
<td>Cholesterol (mmol/l)</td>
<td>&lt; 5</td>
<td>4.5</td>
<td>&lt; 4.5</td>
</tr>
<tr>
<td>LDL cholesterol (mmol/l)</td>
<td>&lt; 3</td>
<td>2.5</td>
<td>&lt; 2.5 (≤ 1.8*)</td>
</tr>
<tr>
<td>Triglyceride (mmol/l)</td>
<td>&lt; 1.7</td>
<td>1.7</td>
<td>&lt; 1.7</td>
</tr>
<tr>
<td>HDL cholesterol (mmol/l), women</td>
<td>&gt; 1.2</td>
<td>1.3</td>
<td>&gt; 1.2</td>
</tr>
<tr>
<td>HDL cholesterol (mmol/l), men</td>
<td>&gt; 1.2</td>
<td>1.0</td>
<td>&gt; 1.0</td>
</tr>
<tr>
<td>BMI (kg/m²), women</td>
<td>&lt; 24</td>
<td>-</td>
<td>&lt; 25</td>
</tr>
<tr>
<td>BMI (kg/m²), men</td>
<td>&lt; 25</td>
<td>-</td>
<td>&lt; 25</td>
</tr>
<tr>
<td>Blood pressure (mm Hg), healthy kidney</td>
<td>≤ 140/85</td>
<td>130/80</td>
<td>&lt;130/80</td>
</tr>
<tr>
<td>Blood pressure (mm Hg), microalbuminuri</td>
<td>-</td>
<td>125/75</td>
<td>&lt;125/75</td>
</tr>
<tr>
<td>Regular physical activity (min/day)</td>
<td>-</td>
<td>-</td>
<td>&gt; 30-45</td>
</tr>
</tbody>
</table>

Note: * Patients with symptomatic CVD,

SNG = Swedish national guidelines, SFD = Swedish Association of Diabetology, ESC = European Society of Cardiology, EASD = European Association for the Study of Diabetes.

HbA1c is presented in Swedish MonoS.
The treatment targets are based on clinical research

The treatment targets are based on findings in clinical research, and new evidence is continuously being found. For this reason, the treatment targets are revised at intervals of a number of years. The studies presented below have had a great impact on treatment and the formulation of treatment targets for patients with type 2 diabetes during recent years.

The UK Prospective Diabetes Study (UKPDS), a ten-year randomized controlled follow-up study of 3,642 newly diagnosed people with type 2 diabetes (mean age 53 years), has had a major impact on the formulation of the treatment targets. Patients were randomized either to intensive or conventional glycaemic treatment. It was found that for every percentage point decrease in HbA1c there was a 37% reduction in the risk of microvascular complications and a 21% decrease in the risk of death related to diabetes (34). Further, it was found that on average, each 10 mm Hg decrease in systolic blood pressure was associated with a reduction in risk between 12% and 19% for both micro- and macrovascular complications (31). The UKPDS has also reported that for each increase of 1 mmol/l in low density lipoprotein cholesterol (LDL cholesterol) there was a 1.57-fold increase in risk of coronary artery disease (CAD), and for each increase of 0.1 mmol/l in high density lipoprotein cholesterol (HDL cholesterol) a 0.15-fold decrease in CAD risk (35).

The Danish Steno-2 Study, a 7.8-year follow-up study of 160 newly diagnosed individuals with type 2 diabetes (mean age 55 years), has also contributed to the knowledge base in diabetes care. The targets in the intensive therapy group were in accordance with the SFD’s proposal for the national treatment targets of HbA1c <5.5% (Swedish MonoS) and cholesterol <4.5 mmol/l, triglyceride <1.7 mmol/l, blood pressure <130/80 mm Hg. The risk of microvascular complications had been reduced by 50% at four-year follow-up, the risk of macrovascular complications had been reduced by 50% at the end of the trial (7.8 years), and a 50% reduction in mortality was reported at 13.3-year follow-up (32, 43, 44).

Above all, the glycaemic control has shown to have an impact on microvascular complications. The Action to Control Cardiovascular Risk in Diabetes (ACCORD) study tested the effect on major cardiovascular disease (CVD) events from intensive glycaemic control (n=5,128) compared to standard glycaemic control (n=5,123). They also studied different treatments of blood lipids and compared intensive systolic blood pressure control of 120 mm Hg with standard systolic blood pressure of 140 mm Hg. A total of 10,251 individuals with type 2 diabetes (mean age 62.2 years) with a ten-year duration of diabetes, at high risk for CVD events, were included in the study (45, 46). After 3.5 years of treatment it was found that the intensive group (HbA1c 5.0%) had a 35% higher cardiovascular death rate than did the standard group (HbA1c 6.0 to 7.0%) (Swedish MonoS), independent of patients’ baseline char-
acteristics. The patients in the intensive group who entered the study with no history of heart attack or stroke, or with HbA$_{1c}$ level ≤7.2% (Swedish MonoS), had fewer combined cardiovascular events during the study than did the patients in the standard group. Another finding was that the two groups differed in their medication: participants in the intensive group used more medication to meet their treatment targets. The intensive group’s treatment target had to be changed to that of the standard group and the data collection is estimated to be finished in 2009 (47). This finding in the ACCORD study does not change the proposal regarding new Swedish treatment targets; rather, it has been considered that it confirms that the treatment for each person needs to be individualized and that high-risk individuals need to be treated carefully (48).

National Diabetes Register

The primary health care centres are encouraged to participate in the National Diabetes Register (NDR) in order to measure quality in diabetes care (26, 49). The NDR was implemented in 1996 as a response to the 1989 St. Vincent declaration requirement to assess the quality in diabetes care (26, 39). The implementation of the NDR has allowed the centres to perform quality control according to the national treatment targets. The centres are able to assess their patients’ possibilities to reach national treatment targets and make comparisons with the population in the register (49). When the register was implemented in Sweden it was unique in Europe, but since then the UK has also implemented a register. In 2004, the British government introduced a financial incentive to follow up the quality of care in primary health care – the Quality and Outcome Framework (QOF), and the majority of patients with type 2 diabetes are now registered in the QOF (50, 51).

In Sweden, participation in the register is voluntary (26). Twelve years after implementation of the NDR, about 80% of centres report data to it. The majority of centres report data on-line, but direct transmission has increased during recent years (52) and will probably contribute to make it easier for centres to participate in the register. Reported data are validated by filtering extreme values (53).

Until 2007 only adults (>18 years) with diabetes were registered in the NDR, but in 2008 children and adolescents with diabetes also began being included in the register (52). Before agreeing to participate, patients are informed about the NDR (26). Demographic information on the patient like date of birth, age at diabetes onset, type of diabetes and treatment, and duration of diabetes is reported. Clinical characteristics of the patients such as HbA$_{1c}$, height, weight, waist measurement, lipids, blood pressure, preventive treatment, various risk factors, diabetes complications and physical activity are also reported. Data are reported to the NDR from the centres at least once a year (52). Even though patient education is a prerequisite for successful diabetes care, no data are reported about the education provided to the NDR.
Patient education in diabetes

Patient education in diabetes – history

Frederick Allen and Elliott Joslin, two leading diabetes specialists in the US, were pioneers within patient education in diabetes during the early 20th century (54, 55).

Frederick Allen introduced the carbohydrate and calorie-restricted diet into the treatment, publishing the “Total Dietary Regulation in the Treatment of Diabetes” in 1919. Elizabeth Hughes was one of Allen’s patients. She was 11 years old when she came to his clinic in 1919; everything she ate was weighed and she was punished if she diverged from the diet. However, Elisabeth did as she was told for the most part and followed her prescribed diet (55). This way of acting has later been defined as “compliance”. Sackett and Haynes suggested a definition of compliance as: “the extent to which a person’s behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice” (56, p. 1427). However, Elisabeth’s life changed and her quality of life was improved when insulin was discovered in 1922 (55).

Elliott Joslin, on the other hand, educated patients on a carbohydrate-restricted diet and regular exercise, and his monograph “The Treatment of Diabetes Mellitus” was published in 1916 (54). Joslin was a pioneer in patient education in diabetes, implementing the team approach and initiating nurses into diabetes care at his clinic. The nurse was responsible for teaching the patients about diet, exercise and treatment. Joslin “believed in empowering patients”, taking the patients’ needs into account and supporting education aimed at patient autonomy (57).

When diabetes is diagnosed it can be labelled as an acute disease, but in the lifelong perspective it is a chronic condition. Frederick Allen’s approach might be appropriate when treating an acute disease. Elliott Joslin’s view of patient education, on the other hand, seems to meet the needs involved in treating chronic conditions. These two leading diabetes specialists can be viewed as an example of two different concepts – compliance and empowerment.

Compliance and empowerment

During the 1970s, the concepts of compliance and empowerment were legitimized. The characteristic feature of compliance has been seen as care providers/superiors giving advice and recommendations while patients/subordinates are expected to follow the advice and recommendations given to them (56). This way of acting is viewed from a “top-down perspective” (58). From this perspective, it is the care providers who define the problems, develop strategies to resolve the problem and involve the patients...
in taking action to follow a plan that the care providers have made for them. Learner asserts that the reason compliance has been so strongly associated with patients having to “slavishly follow orders depends on limitation of informed consent as a guiding principle in decision-making” (56, p. 1428). Sackett and Haynes considered that three criteria should be fulfilled “prior to any attempts to change patient behavior. Firstly, the diagnosis had to be correct, secondly, the proposed therapy had to do more good than harm and thirdly the patient had to be an informed willing partner” (56, p. 1427).

In the 1980s it was discussed that a lack of communication between care providers and patients had a negative influence on the patients’ behaviour and was one of the reasons they did not comply with the advice given to them (59). Findings in research in recent years indicate that this lack of communication between care providers and patients still exists. In a qualitative study, Holmström et al. (60) found that 169 care providers from 20 primary health care centres presented only the information they considered relevant to the patient and expected the patients to follow their instructions. In focus-group interviews with 30 GPs in primary health care, Brown et al. (61) found that they felt they had informed their patients but that the patients did not adopt the information provided. The patients, on the other hand, found it difficult to follow the advice or information given by their care providers (62, 63).

The concept of empowerment already existed in the 1920s but was not used in scientific literature until the late 1970s. Pioneer Barbara Solomon’s commitment and work among underrepresented populations in the US described in her book “Black Empowerment: Social Work in Oppressed Communities”, published in 1976, introduced the concept as a framework for social work practice. Its origin, based on the concept of power, is considered to be the reason it has become popular to use (64). The concept has been used in many different contexts in society, and perhaps not always in the context it was intended for. In health care, for example, it has been used as a cost-reduction concept based on the thought that increased power among patients reduces their need for health care (65).

The empowerment concept in the educational sciences has developed out of Brazilian teacher and philosopher Paulo Freire’s work in Latin America. Freire taught poor people to read and to think critically, and also struggled like Solomon for the oppressed (66). Freire asserted that the first stage towards transformation of power is that the oppressor and the oppressed become aware of their condition. As long as the oppressor remains unaware of the condition he/she continues to have control over others, and as long as the oppressed remains unaware he/she accepts the control. It is first when the oppressed become aware of their situation that they are able to take control over their lives (67).

Rappaport defined empowerment as a process whereby people gain mastery and take control over their own lives. Empowerment is, according to
Rappaport, a process through which the individual him/herself takes control of his/her own situation. The components of this process take on different forms for different individuals and contexts, and the results differ both regarding the area in which the process occurs and among different individuals. For some individuals it can mean a sense of control while for others it can lead to real control (68). In the empowerment process, co-operation and trust are essential. In this process, care providers relinquish their power and enable patients to gain their power (69). The problems and solutions jointly arise from what we today call a “bottom-up” perspective (58).

Patient education in diabetes – today

Anderson et al. at the Michigan Diabetes Research and Training Center (MDRTC) introduced empowerment into patient education in diabetes at the beginning of the 1990s in the US (70-72). They implemented empowerment group education programmes in diabetes (empowerment programme) and evaluated their empowerment programme in a randomized wait-listed control-group study. A total of 64 patients with type 1 and type 2 diabetes participated for six weeks in 2-h weekly group sessions. Six weeks after completion of the empowerment programme, an improvement in self-efficacy and glycaemic control was reported among the patients who had participated in the programme compared to those in the wait-listed control group (73).

Evaluation of patient educational interventions for people with type 2 diabetes during the 21st century indicates that there is a trend to actively involve patients in their care in accordance with the empowerment philosophy.

The effects of patient education for people with type 2 diabetes have been evaluated in several systematic reviews. Deakin et al. (74) compared group education programmes with routine diabetes care, a review that yielded 1,532 patients from 11 studies. They found that group-based programmes in favour of routine treatment improved patients’ diabetes knowledge, reduced HbA1c at four to six months by 1.4%, at 12-14 months and two years by 0.8% and 1.0%, respectively, and reduced body weight at 12 months by 1.6 kg. Norris et al. (75) evaluated the efficacy of self-management education on patients’ glycaemic control, including a total of 4,263 patients from 31 studies in their analysis. The authors found that the intervention decreased HbA1c by 0.76% more than the control group at immediate follow-up and by 0.26% at ≥ 4-month follow-up. Further, they reported that an average of 23.6 hours of contact time between the care provider and patient was needed to achieve one percentage point reduction in HbA1c. In their review of 2,186 patients from 13 studies, Loveman et al. (76) examined the clinical effectiveness of patient education models in adults with type 2 diabetes. They reported that educational programmes delivered over longer intervals and/or provided with more frequent contact between patients and care providers seem to have
the best impact on patients’ metabolic control. These interventions have been performed in primary health care, outpatient and community settings.

A summary of randomized controlled trials (RCTs) in patient education for people with type 2 diabetes in Europe, published in the 21st century, is presented in Table II as a complement to these reviews (77-88). Only three of the studies were performed in a primary health care setting (77, 87, 88). The interventions have mostly been provided in the context of a group education programme and the empowerment philosophy has been used as the theoretical basis for the programmes. In four of the studies (78, 79, 85, 88), the baseline values differ between the two study groups. However, in three of the studies (78, 85, 88) adjustments have been made for the difference in the baseline values, while this is unclear in the fourth (79). One of the studies had a high level of drop-outs between initial recruitment and reporting of findings. This study had, on the other hand, the largest study size and a follow-up time of six years (77). Follow-up times differ considerably between the studies, which makes it difficult to draw conclusions. It seems, however, that regular encounters between care providers and patients over a longer period of time have an impact on patients’ outcomes. This is in line with the findings by Norris and Loveman et al. (75, 76).

Learning how to learn

Patients with diabetes need support in discussing and understanding their condition (37). Care providers have been found to need support in starting to use a new method or approach (70, 89-91). Pill et al. (91) found that only 19% of care providers applied the method they had been trained to apply. Anderson et al. found that it was not easy for care providers to “change deeply integrated behaviors” and apply a new approach (70, p. 589). Kinnmonth et al. (90) reported that care providers lost focus on the disease when they applied a patient-centred approach. Doherty et al. (89) concluded that after care providers had participated in a 40-h training programme some of them had an easier time applying the new approach than others did. In these studies, the care providers had been educated in methods or approaches to apply in patient education in diabetes.

Theories of adult learning are extensive. The theories presented below have been chosen to gain insight into and an understanding of how adult learning can be viewed. Adult learning is considered to be different from young peoples’ learning, as adults have lifetime experiences. The adult learning theory is called andragogy, and is defined as “the art and science of helping adults learn” (92, p. 213). Malcolm Knowles is seen as “the father of adult learning in the 20th century”; He wrote the books “The Modern Practice of Adult” and “The Adult Learner” at the beginning of 1970s (93). Knowles presents five guiding principles for adult learning: “adults are inde-
Table II. Randomized controlled trials in patient education for people with type 2 diabetes in Europe, published in the 21st century.

<table>
<thead>
<tr>
<th>Study</th>
<th>Study size</th>
<th>The professionals’ preparation prior to and during the intervention</th>
<th>Intervention</th>
<th>Time-point</th>
<th>HbaA1c (%) mean or median</th>
<th>Difference between I and C p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Olivarius et al. (77)</td>
<td>649 614</td>
<td>GPs: Continuing feedback to the GPs during the intervention.</td>
<td>Individual counselling: Every third month. Negotiating realistic goal setting with the patients.</td>
<td>Baseline 6 years</td>
<td>10.2 10.2</td>
<td>NS p &lt; 0.0001</td>
</tr>
<tr>
<td>Goudswaard et al. (78)</td>
<td>28 30</td>
<td>DSNs: No preparation prior to or during the intervention reported.</td>
<td>Individual counselling: Six 15-45-minute sessions over a period of six months. Total of 2.5 h. Collaborative and mixed.</td>
<td>Baseline 7.5 months 18 months</td>
<td>8.2 8.8</td>
<td>- p &lt; 0.05 NS</td>
</tr>
<tr>
<td>Cooper et al. (79)</td>
<td>53 36</td>
<td>DSNs: Six days training prior to the intervention, and DSNs were provided with a teaching manual. Group education: Eight weekly 2-h sessions. Total of 16 h. Look After Yourself - programme. The philosophy of empowerment.</td>
<td></td>
<td>Baseline 6 months Baseline 1 year</td>
<td>7.8 7.9 7.7 7.9</td>
<td>- p = 0.005 NS</td>
</tr>
<tr>
<td>Trento et al. (80-82)</td>
<td>56 56</td>
<td>GPs and an educator (the researcher): The educator spent six months before the project observing patients. Group education: Four 50-minute sessions every third month for five years. Individual counselling at the end of the sessions when needed. Total of about 16 h. Systematic education approach.</td>
<td></td>
<td>Baseline 2 years 4 years 5 years</td>
<td>7.4 7.5 7.0 7.3</td>
<td>NS P &lt; 0.002 P &lt; 0.001 P &lt; 0.001</td>
</tr>
<tr>
<td>Sarkadi et al. (83)</td>
<td>39 38</td>
<td>Trained pharmacists assisted by DSN: Three-day training course. Continuing feedback every six months during the intervention. Group education: Study circles starting with two whole days followed by 10-12 three-hour sessions. Total of about 46-52 h. Experience-based.</td>
<td></td>
<td>Baseline 6 months 1 year 2 years</td>
<td>6.4 5.7 6.2 6.0</td>
<td>NS P &lt; 0.05 NS P &lt; 0.01</td>
</tr>
</tbody>
</table>
### Table II. continued

<table>
<thead>
<tr>
<th>Study</th>
<th>Study size</th>
<th>The professionals’ preparation prior to and during the intervention</th>
<th>Intervention</th>
<th>Time-point</th>
<th>HbA1c (%) mean or median</th>
<th>Difference between I and C p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I</td>
<td>C</td>
<td></td>
<td>Baseline</td>
<td>I</td>
<td>C</td>
</tr>
<tr>
<td>Deakin et al. (84)</td>
<td>157</td>
<td>157</td>
<td>Dietician (the researcher): No preparation prior to or during the intervention reported.</td>
<td>Baseline</td>
<td>7.7</td>
<td>7.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Group education: Six weekly 2-h group sessions. <strong>Total of 12 h.</strong> The philosophy of empowerment and discovery learning theories.</td>
<td>4 months</td>
<td>7.4</td>
<td>7.8</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>14 months</td>
<td>7.1</td>
<td>7.8</td>
</tr>
<tr>
<td>Kultz et al. (85)</td>
<td>63 (B)</td>
<td>66 (C)</td>
<td><em>Health psychologists</em>: Training in conducting the treatments.</td>
<td>Baseline</td>
<td>8.1 (B)</td>
<td>7.6</td>
</tr>
<tr>
<td></td>
<td>64 (A)</td>
<td></td>
<td><strong>Group education (A)</strong>: Didactic-oriented four 1.5-h sessions. <strong>Total of 6 h.</strong></td>
<td>3 months</td>
<td>7.8 (C)</td>
<td>7.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>Group education (B)</strong>: Self-management/empowerment approach, twelve 1.5-h sessions. <strong>Total of 18 h.</strong></td>
<td>15 months</td>
<td>7.3 (B)</td>
<td>7.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>Group education and individual counselling (C)</strong>: Self-management/empowerment approach, twelve 1.5-h sessions (six of the sessions in individual counselling). <strong>Total of 18 h.</strong></td>
<td></td>
<td>7.1 (C)</td>
<td>7.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>7.4 (B)</td>
<td>7.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>7.6 (C)</td>
<td>7.7</td>
</tr>
<tr>
<td>Hörnsten et al. (86, 87)</td>
<td>44</td>
<td>60</td>
<td>DSNs (one of them the researcher): Reflective group discussion for a total of 36 h.</td>
<td>Baseline</td>
<td>5.7</td>
<td>5.8</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>Group education</strong>: Ten 2-h group sessions. <strong>Total of 20 h.</strong> With focus on explanatory models, coping and patient centeredness.</td>
<td>1 year</td>
<td>5.4</td>
<td>6.4</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5 years</td>
<td>5.7</td>
<td>7.1</td>
</tr>
<tr>
<td>Davies et al. (88)</td>
<td>437</td>
<td>387</td>
<td><em>Health care professional educators</em>: Two days training in delivering the programme.</td>
<td>Baseline</td>
<td>8.3</td>
<td>-1.23*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>Group education</strong>: One day or two half-day group sessions. <strong>Total of 6 h.</strong> Structured programme using Laventhal’s common sense theory, the dual process and social learning theory. The philosophy of empowerment.</td>
<td>4 months</td>
<td>-1.23*</td>
<td>0.93*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>8 months</td>
<td>-1.50*</td>
<td>-1.11*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1 year</td>
<td>-1.49*</td>
<td>-1.21*</td>
</tr>
</tbody>
</table>

Note: I = Intervention group, C = Control group, * difference between baseline and follow-up time.
dependent and self directing, they have accumulated a great deal of experience, they value learning that integrates with the demands of their everyday life, they are more interested in immediate, problem centred approach than in subject centred ones, and they are more motivated to learn by internal drives than by external ones” (92, p. 213). The concept of adult learning has many synonyms, but “common for all concepts is that they contain an element of change either on the emotional, intellectual or behaviour level” (94, p. 23).

Marton (95) talks about deep and surface approaches to learning. The deep approach implies having an understanding of what you have learned and being able to put it into context. It is easier to put learning into context when you have knowledge about the issue. The surface approach, on the other hand, entails learning for the sake of learning.

Moxnes (94) asserts that adults learn mostly by doing something. The more meaningful they consider what they are doing to be, the more they learn. Learning takes place when people experience that the issue has meaning for their own aims and goals. Moxnes talks about learning as a cyclic lapse that is constantly occurring. This lapse starts with active experimentation based on our frames of reference. This experimentation will be subject to reflection, which leads to an analysis that can lead to a change in our frames of reference. The changed frames of reference will be a point of departure for new experiments, and so on. Moxnes also discusses another aspect of learning, ”un-learning”. This aspect of learning means leaving old convictions and opinions - getting rid of old knowledge. While new learning is built upon old experiences, ”un-learning” needs to take place in the light of the new knowledge and within old concepts and frames of reference. He considers that besides old experiences, some form of individual insight about the result the change will have for you, as well as motivation, are required to convert the insight into action.
Rationale of the thesis

It has been common that patients with type 2 diabetes have been referred to a one-week programme at the hospital outpatient clinic when they have been considered to be in need of insulin supplementation. In the late 1990s, the diabetes team responsible for the outpatient care at Västerås Central Hospital (in the county council of Västmanland) in central Sweden participated in a two-day workshop in empowerment arranged by the Diabetes Education and Research Centre (LUCD), Karolinska Hospital, Sweden. LUCD had adopted the approach from the MDRTC in the US. At that time I worked as a dietician on the diabetes team at Västerås Central Hospital, and participated in the workshop. The team wanted to learn how to support and strengthen patients’ own resources for managing their lives with the disease. The empowerment approach was implemented in the one-week programme for patients with type 2 diabetes, and patients’ experiences of participating in the programme were evaluated. Data were collected in individual interviews, with 11 patients participating in the interviews. The patients had ten years experience of living with the disease. The data from the interviews indicated that the one-week programme had contributed to giving them insight into what their disease was about, but they asked: “Why have we not been told this earlier?” (96). They should not have needed to live for ten years with the disease before they began understanding what type 2 diabetes was about.

For this reason, the 18 primary health care centres in the hospital’s catchment area were asked to participate in a two-day empowerment workshop offering support in arranging empowerment programmes at their centres. Of the 18 centres, ten responded that they were interested, and participated in the workshop. Of the ten centres that had participated in the workshop, seven implemented an empowerment programme. At that time, Anderson et al. were the only ones who had evaluated the implementation of the empowerment approach in diabetes. They evaluated diabetes educators’ experiences of participating in their three-day empowerment workshop (70) and their empowerment programme in a randomized wait-list controlled six-week follow-up study (73). We wanted to evaluate the care providers’ view on implementing the empowerment programme in a defined primary health care setting in central Sweden and to quantitatively and qualitatively evaluate the implementation of the programme to get a nuanced picture of this new approach in diabetes care. To increase our understanding of how patient education is provided for people with type 2 diabetes in primary health care in the whole of Sweden, not only in this defined setting in central Sweden, we needed to conduct a national survey.
Aim

General aim

The general aim of this thesis was to evaluate different aspects of patient education for people with type 2 diabetes in Swedish primary health care.

Specific aims

The specific aims of the different papers were as follows:

– to gain insight into and understanding of general practitioners’ and diabetes specialist nurses’ views on implementing an empowerment programme at their primary health care centres and to explore opportunities for and barriers to its implementation (Paper I).

– to evaluate the impact of an empowerment programme on patients’ confidence in diabetes knowledge, self-efficacy, satisfaction with daily life, BMI and glycaemic control compared with the impact of individual counselling in routine diabetes care on the same factors at a 1-year follow-up (Paper II).

– to explore patients’ experiences of participating in the empowerment programme or receiving individual counselling in routine diabetes care (Paper III).

– to describe how patient education is arranged in Swedish primary health care and to assess whether type of education and individual goal setting have an impact on patients’ possibilities to reach recommended national treatment targets (Paper IV).
Methods

Study designs

Qualitative and quantitative designs have been used in this thesis. An overview of designs and methods is presented in Table III. The papers are based on samples from primary health care centres in the county council of Västmanland in central Sweden (Papers I-III) and from Swedish primary health care (Paper IV).

Table III. An overview of designs, methods and data analyses in the four papers.

<table>
<thead>
<tr>
<th>Paper</th>
<th>Data collection (Year)</th>
<th>Study design</th>
<th>Primary health care centres / participants</th>
<th>Data collection</th>
<th>Data analyses</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>2002</td>
<td>Descriptive qualitative study</td>
<td>6 / 16</td>
<td>Focus-group interviews 90-120 minutes</td>
<td>Constant comparative method</td>
</tr>
<tr>
<td>II</td>
<td>2001-2002</td>
<td>Randomized controlled trial</td>
<td>7 / 101</td>
<td>27-item study-specific questionnaire HbA1c and BMI</td>
<td>Mann-Whitney U-test Student’s t-test Chi-square ANCOVA</td>
</tr>
<tr>
<td>III</td>
<td>2002</td>
<td>Descriptive qualitative study</td>
<td>7 / 28</td>
<td>Individual interviews 30-45 minutes</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>IV</td>
<td>2006</td>
<td>National survey</td>
<td>485 / 91,637</td>
<td>Swed-QOP questionnaire NDR</td>
<td>Qualitative content analysis Descriptive analysis Stepwise multiple linear regression analysis with backward selection</td>
</tr>
</tbody>
</table>

Study populations

Paper I

At seven primary health care centres in central Sweden, seven GPs and 12 DSNs participated in an empowerment workshop and in a pilot group practising leading empowerment group sessions. All 19 care providers consented
to participate in focus-group interviews after they had implemented two empowerment programmes at their centres. Of these, two GPs and one DSN withdrew due to sick leave, vacation and misunderstanding concerning appointment time, respectively. This meant that 16 care providers, five GPs (two females and three males) and 11 DSNs (all females) from six centres participated in the study. The mean age of the five GPs was 46 years and of the 11 DSNs 53 years. The GPs and DSNs had worked in health care approximately 17 and 30 years, respectively. One of the 16 care providers had arranged group education previously.

Paper II

Patients at the seven centres that had implemented the empowerment programme participated in an RCT, being randomly assigned either to the intervention (empowerment programme) or to the control group (individual counselling in routine diabetes care). To avoid threats to internal validity, a comparison group was selected from four of the 11 centres that had not participated in the empowerment training.

Inclusion criteria in the study were: receiving dietary or OHA; ≤ 75 years of age; HbA1c value ranging from 6.5% to 10%; diabetes duration of at least one year; considered able to participate in a diabetes group and able to understand the Swedish language. Exclusion criteria were: known alcohol abuse; known mental disability; presence of serious disease (stroke, late stage of cancer) and having previously participated in group education.

Altogether, 170 patients who fulfilled the study criteria were asked to participate in the RCT. They were first informed by mail about the study, and some days later the DSNs responsible for the data collection at the centre contacted them by phone. Of the 170 patients, 69 declined participation. The remaining 101 who gave their consent to participate were scheduled for a visit to their centres prior to the intervention to perform the baseline measures. At this visit, each patient was randomly assigned to one of the two groups. A research assistant had performed the randomization in blocks of four for each of the seven centres. A closed-envelope system was used, whereby the envelopes were drawn in consecutive order after the baseline measurements.

Eight patients withdrew from the intervention group before the one-year follow-up. Thus, 42 patients remained in the intervention group. Five patients withdrew from the control group before the one-year follow-up, leaving 46 patients in that group. A flow chart showing the participants throughout the RCT is presented in Figure 1. The mean age of the patients in the intervention group was 62.4 years, and they had lived a mean of 6.5 years with the disease. The mean age of the patients in the control group was 63.7 years and they had lived a mean of 6.7 years with the disease.
The comparison group was selected from the four centres not involved in the empowerment programme to control for bias. At these four centres, the 59 patients who fulfilled the study criteria were asked to participate in the study. Twenty patients declined participation and four withdrew before the one-year follow-up (one was diagnosed with cancer, three were referred to a medical clinic). The comparison group comprised 35 patients. No statistically significant differences were found between the comparison and control groups in patient characteristics at baseline and the outcome measures. The findings indicated that no contamination seemed to have occurred in the control group.

Figure 1. Flow chart showing participants throughout the randomized controlled trial in Paper II.
Paper III

In total, 28 patients participated in an interview study. Of these, 14 patients had participated in the empowerment programme and 14 had received individual counselling in routine diabetes care (one male and one female from each group at the seven centres) in the RCT. The mean age of the patients in the empowerment programme was 61.9 years and they had had the disease a mean of 5.8 years. The mean age of the patients in the individual counselling in routine diabetes care was 64.9 years and they had had the disease a mean of 6.7 years.

Paper IV

Two data sources have been used to collect data from Swedish primary health care in 2006: a questionnaire used in a Swedish national survey of the quality and organization of diabetes care in primary health care (Swed-QOP questionnaire) and patients’ data reported to NDR. In total, 957 health care centres were registered in the Health & Medical information service address register. Of these 36 centres had been withdrawn, meaning that 921 centres were eligible to participate in the study. Centres that had not reported any patients or that had reported <30 diabetic patients to NDR (n=199) were excluded. Two hundred and thirty-seven centres did not respond to the questionnaire. In total 485 centres, with 91,637 diabetic patients in all, were included in the study. A flow chart of the centres is shown in Figure 2. The mean age of the patients was 68 years and they had had diabetes a mean of 8.6 years.

Figure 2. Primary health care centres in the Swedish national survey.
Intervention (Papers I, II, III)
The care providers’ preparation in becoming facilitator in empowerment programme

During 2000 the 19 care providers at the seven primary health care centres participated in a two-day workshop arranged by LUCD. Prior to the workshop, the care providers had been encouraged to follow a two-day diabetes regime to increase their understanding of how it felt to follow instructions given to them and to live with the condition. The educator at the workshops was the manager at LUCD and was responsible for the implementation of the empowerment programme in Sweden, and the author assisted as a supervisor.

The programme in the workshop was designed to provide prospective facilitators with the theoretical framework of empowerment, motivation and learning principles. The practical part included training in being facilitators in the encounter with other participants in videotaped, individual counselling. After the workshop, the care providers practised being facilitators in a group with at least four diabetic patients in four group education sessions (pilot programme) at their centres. The author participated in the pilot programme as an observer in at least one group session at each centre, and videotaped three of these sessions. Observations showed that the care providers/facilitators needed to improve their listening skills as well as their way of posing questions, problem solving, goal setting, and supporting patients in behavioural changes and medical treatment. Feedback on these observations was given in meetings with the care providers/facilitators at each centre. Further, the care providers/facilitators participated in three half-day follow-up meetings to discuss the approach and the content of the empowerment programme, and to exchange experiences. The first half-day follow-up meeting took place during the latter part of 2000, the second in the spring of 2001 and the third in the autumn of 2001.

The empowerment programme

One GP and one or two DSNs were facilitators in the programme at each centre. The design of the empowerment programme, based on empowerment philosophy and adult learning principles, is presented in Table IV.

The first education session started with an introduction and a discussion of the patients’ expectations of the programme. An important part of the sessions was allowing the patients to feel free to ask questions and talk about their own experiences. One or two themes about self-care and the disease were discussed during each session. The sessions ended with the facilitators encouraging the patients to reflect upon their experience regarding the behavioural changes they needed to undertake in their self-care. After the first
session, the intention was to begin each session with a discussion of the patients’ reflection upon and evaluation of their experiences of behavioural change since the previous session.

*Table IV. The empowerment programme.*

| The groups:     | Number of diabetic patients in each group: 5-8 patients  
|                | Number of sessions: 3-4 at weekly intervals and one follow-up  
|                | Duration of each session: 2-3 hours  
| The intention of the programme was to enable patients to: | Exchange experiences  
|                | Discuss how to live with the disease with others who have the same condition  
|                | Explore their problems  
|                | Identify feasible self-care changes  
|                | Discuss strengths and barriers to making behavioural changes  
|                | Be assured of their own resources for making changes  
|                | Identify and set short and long-term goals  
|                | Make an action plan to reach these goals  
|                | Reflect upon and evaluate their behavioural change experiences  
| Theme discussions: | General issues concerning the disease  
|                | Blood glucose monitoring  
|                | Diet  
|                | Physical activity  
|                | Medical treatment  
|                | Foot care  
|                | Prevention of complications  

Data collection

Focus-group interviews (Paper I)

Prior to the data collection, the GPs and DSNs had participated in the care providers’ preparation in becoming facilitators in the empowerment programme. Besides the pilot programme, they had implemented one more programme at their centre. They received a personal written invitation containing time and place one month before their participation in the focus-group interviews. The interviews were conducted in a place that was neutral to the care providers, and data were collected three to nine months after implementing the programme.

Prior to the interviews, the questions were tested by one of the members of the diabetes team who had implemented the programme at Västerås Central Hospital.

Three focus-group interviews were carried out, one with the GPs and two with the DSNs. Open-ended interview questions were used with a focus on
the opinion, application, and opportunities for and barriers to implementing empowerment programmes at their centres. The moderator of the discussions was a DSN and an educator at LUCD. Two assistants (the author and a Social Sciences master student) helped the moderator by tape recording the interviews and summarizing the discussions. The same moderator and assistants participated in all three focus-group interviews. The tape-recorded interviews were transcribed verbatim.

A 27-item study specific questionnaire (Paper II)

A 27-item study-specific questionnaire (seven questions about confidence in diabetes knowledge, ten questions about self-efficacy and ten about satisfaction with daily life) was used to evaluate the programme (see Appendix). The seven questions about confidence in diabetes knowledge were constructed for the study, with answers being given on 100 mm visual analogue scales (VAS). Most of the ten questions on self-efficacy had been used in earlier studies (97); these answers were also given on 100 mm VAS. Several of the ten questions concerning satisfaction with daily life were adapted from the World Health Organization Quality of Life Assessment (98). The answers, given on five-point scales, were linearly transformed to a 0-100 scale to facilitate presentation and comparison with the VAS. Higher values indicated that the patients had more confidence in diabetes knowledge and greater self-efficacy, and were more satisfied.

Individual interviews (Paper III)

The author contacted all 28 patients by phone within two weeks to agree upon a time and place for the interviews. All interviews except one were conducted at the patients’ primary health care centre or at a centrally located centre. One interview was conducted at the patient’s home, due to the patient’s limited mobility.

Prior to these interviews, four pilot interviews were performed to test the interview guide - two with patients who had participated in the empowerment programme and two with patients who had received individual counselling in routine diabetes care (one male and one female in each group).

Semi-structured interviews were performed once with each of the 28 patients. The main theme discussed was the patients’ experiences of the diabetes education, and additional themes discussed were: a) learning, b) behavioural change and c) self-care management. The author interviewed all participants, and the interviews were tape-recorded and transcribed verbatim.
Swed-QOP questionnaire (Paper IV)

The Swed-QOP questionnaire is based on questions from questionnaires used in primary health care in Sweden (99) and the UK (24, 100).

In February 2007 the questionnaire was sent, together with a cover letter and pre-paid envelope, to 957 managers at the primary health care centres registered in the Health & Medical information service address register. After two weeks a reminder letter was sent to the 760 managers who did not respond to the first request, and after another three weeks the reminder letter, questionnaire and pre-paid envelope were sent to the 560 managers/DSNs who had not responded to the second request. Telephone contact was made after four months with the 357 centres that had not yet responded to the request. The aim of the telephone contact was to get the name of a DSN or another person responsible for the diabetes care at the centre. During the summer an additional reminder letter, questionnaire and pre-paid envelope were sent to this person. Collection of the questionnaires was completed at the end of August 2007.

The questionnaire was scanned into the computer and verified, and answers to the open questions were handled manually. When this procedure was finished the data were sent to the NDR, where the statistician included the latest reported patient data they had received from the centres in 2006. Before the author responsible for the study received the data, it was decoded by the statistician.

The questions in the Swed-QOP questionnaire are shown in Table V. The questions used in this study addressed the list size of centres, personnel resources, type of patient education in diabetes and individual goal setting.

Table V. Questions in the Swed-QOP questionnaire.

<table>
<thead>
<tr>
<th>List size of primary health care centres</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of patients at the centres or the reported catchment area</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Personnel resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of whole time equivalent GP</td>
</tr>
<tr>
<td>Number of hours DSN spent per week providing care to patients with diabetes</td>
</tr>
<tr>
<td>Number of diabetic patients</td>
</tr>
<tr>
<td>Having diabetes responsible GP</td>
</tr>
<tr>
<td>Having diabetes responsible DSN</td>
</tr>
<tr>
<td>Having DSNs with post-graduate education in diabetes given on a scale from 0 to &gt;30 ECTS</td>
</tr>
<tr>
<td>Other resources within and outside the centre to which they could refer patients</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Way of working</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having and using regional and/or local guidelines</td>
</tr>
<tr>
<td>Screening for long-term complications</td>
</tr>
<tr>
<td>Time spent with each patient during visits to the GP and nurse/DSN</td>
</tr>
<tr>
<td>Routines for starting insulin treatment</td>
</tr>
<tr>
<td>Follow-up system</td>
</tr>
<tr>
<td>Type of patient education</td>
</tr>
<tr>
<td>Individual goal setting (HbA1c, blood pressure, lipids and lifestyle)</td>
</tr>
<tr>
<td>NDR registration</td>
</tr>
<tr>
<td>Example of quality work and the centre’s point of view</td>
</tr>
</tbody>
</table>
HbA\textsubscript{1c} and BMI (Papers III, IV)

In Sweden, HbA\textsubscript{1c} is measured using MonoS, a high-performance liquid chromatography method. The Swedish HbA\textsubscript{1c} can be converted to DCCT standard with the formula: \(0.923 \times \text{HbA}_{1c} \text{(MonoS)} + 1.345\) (101).

Height and weight were measured and BMI was calculated as weight in kilograms divided by the square of height in meters.

National treatment targets (Paper IV)

During the data collection period, treatment targets in Sweden were for HbA\textsubscript{1c} <6.5\%, BMI <25 kg/m\textsuperscript{2}, cholesterol <5.0 mmol/l, blood pressure \(\leq 140/85\) mm Hg (40).

Physical activity (Paper IV)

During the data collection period, the general physical activity recommendation in Sweden was three to five times a week.

Data analyses

In the thesis, qualitative (Papers I, III, IV) and quantitative (Papers II, IV) analyses were used. The data from the focus-group interviews were analysed using constant comparative method of Glaser and Strauss (102). The data from the individual interviews and the answers to the open-ended questions in the Swed-QOP questionnaire were analysed using qualitative content analysis, according to Graneheim and Lundman (103). The findings from the qualitative analysis of the answers on the open questions in the Swed-QOP questionnaire were used in the quantitative analyses. For the quantitative data analyses, the Statistical Package for the Social Sciences (SPSS, version 14.0, SPSS Inc., Chicago, IL, USA) for Windows was used. For all analyses, a two-tailed p-value <0.05 was regarded as significant and 95\% confidence intervals were given when appropriate.

Qualitative data analyses (Papers I, III, IV)

All data from the three focus-group interviews in Paper I were collected before the analysis started. The text of each focus-group interview was read to gain a sense of wholeness. After this, the open coding was started through reading each transcript sentence by sentence. Examples of questions the researchers asked when they analysed the transcripts were “What expresses this phenomena or event?”, “What similarities and differences can we see in the phenomena or event?”, “What is the pattern or story?”, “What concepts
or properties express the phenomena or events?". The analysis process went forward as well as backward. When data from the three focus groups were compared, a pattern grew that focused on the main theme and the core and sub-categories.

In Paper III, both manifest and latent messages were used in the qualitative content analysis of the data from the 28 individual interviews. All texts were read through several times to apprehend the material in its entirety. Thereafter, the texts from each of the two groups were read through several times to grasp the material in each group. The first four steps in the analysis process from meaning unit, condensed meaning unit and codes to sub-categories were performed separately for each group. Thereafter, the sub-categories in the two groups were compared. This comparison brought forth our suggestion of categories representing data in each group (step five) and main categories representing data from the two groups (step six). An example of the analysis process is shown in Table VI.

In Paper IV, manifest messages were used in the qualitative content analysis of four open-ended questions in the Swed-QOP questionnaire about how patient education is arranged in Swedish primary health care. The answers were read through several times to grasp the material in its entirety. The analysis started through the identification of statements that described how patient education is arranged at the centre. The statements were condensed to shorten the text without losing its message. The condensed text was then labelled with a code representing its content. Similarities and differences between the codes were compared to identify categories represented in the data. These categories were not static, as they could change if new phenomena appeared in the data.

Quantitative data analyses (Papers II, IV)

In the RCT in Paper II, both per protocol and intention-to-treat (ITT) analyses were performed. The primary end point was HbA1c. A power calculation (80% power at the 0.05 significance level) showed a need for 51 patients in each group to detect a difference in mean HbA1c of one percentage point (SD 1.8). A factor analysis with varimax rotation was used to test the construct validity of the 27-item study-specific questionnaire. This analysis yielded three factors, all of which had eigenvalues above 1.0 (2.1-7.6), and explained 78% of the variance.

We used analysis of covariance (ANCOVA) adjusted for baseline values to estimate between-group differences in change in the parametric variables BMI and HbA1c (104).
Table VI. Example of the qualitative content analysis process.

<table>
<thead>
<tr>
<th>Step one: Meaning units</th>
<th>Step two: Condensed meaning units</th>
<th>Step three: Codes</th>
<th>Step four: Sub-categories</th>
<th>Step five: Categories</th>
<th>Step six: Main categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>At first I didn’t want to know about actually how the others were sick… I sort of thought it was none of my business, then it became the type of atmosphere that made it not feel strange. I told about what I did and how I felt and they told about their situations. (Peter)</td>
<td>Felt from beginning that it was each person’s own business, but the atmosphere contributed to it becoming natural to tell each other</td>
<td>Atmosphere invited to communication</td>
<td>Open environment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>You sit and talk about different things and then you think I should ask about that and then you actually don’t feel stupid in the same way. I can’t ask about something stupid then. But you have it sort of like that you dare to ask questions. (Regina)</td>
<td>When you’re sitting and talking you don’t feel stupid and instead dare to ask questions</td>
<td>You dare to ask questions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being part of the group, so to speak, that’s given so much, so it still happens that I think about them and wonder how they feel. Bonus points for having a fellowship with them. (Lisa)</td>
<td>Be able to be one of the group and feel fellowship with them</td>
<td>Experience fellowship</td>
<td>Sense of community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having contact with other people and being able to participate and get some answers to your own questions, because otherwise you feel rather alone when you’ve been at home. (Tora)</td>
<td>Have contact with other people because you otherwise feel alone</td>
<td>Have contact with other people</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receive a tremendous amount of support not only in the negative part where you think you’re insufficient, but also encouragement… Tremendous amount of support in the group from not only personnel but participants as well. (Josefina)</td>
<td>Receive great amount of support in what you are not satisfied with as well as encouragement from both personnel and participants</td>
<td>Support from both personnel and participants</td>
<td>Support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>You encourage each other, like when you see that somebody is having a hard time. (Regina)</td>
<td>You encourage each other</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In Paper IV, the Pearson correlation coefficient was used for continuous variables and Cohen’s kappa for discrete variables in the reliability test of the Swed-QOP questionnaire. Stepwise multiple linear regression analyses with backward selection were performed, with HbA1c, BMI, cholesterol, blood pressure and physical activity as dependent variables. The list size of centres, personnel resources, type of patient education and individual goal setting were independent variables.

Validity and reliability

Four researchers participated in the qualitative analysis process to decrease the subjectivity in the data interpretation, and citations were used to allow the reader to judge credibility (Papers I, III). The findings of the focus-group interview analysis were presented to the five GPs and the 11 DSNs, who agreed with them.

The seven GPs and 12 DSNs at the seven centres could be responsible for the care of patients in both the intervention and control groups in the RCT (Paper II). To reduce threats to internal validity, a comparison group was selected from four centres not involved in the empowerment programme. Since the 27-item questionnaire was study-specific, several attempts were made to validate it; as a whole, it was tested in 34 patients participating in the pilot programme. A factor analysis was performed to test its construct validity. The internal consistency of the three domains found in the factor analysis was estimated – they were homogenous with a Cronbach α above 0.79.

A reliability test of the Swed-QOP questionnaire (Paper IV) was performed among ten DSNs and ten primary health care managers at ten centres and showed a correlation between -0.316 and +1.0. The questions with low reliability were adjusted or reconstructed, and the instructions were made clearer. Two researchers, independent of each other, analysed a random sample of 20 responses to the four questions about how patient education is arranged at the centres. The interrater reliability agreement was 85%.

Ethical considerations

The study designs for all papers were approved by the Research Ethics Committee at Uppsala University: Paper I (Dnr 02-038), Paper II (Dnr 00-412), Paper III (Dnr 02-127), Paper IV (Dnr 2006:335).

All participants were informed about the aim of the studies, that participation was voluntary and that they could cease participation whenever they wanted. All participants gave their informed consent to participate in the studies (Papers I-IV). The patients registered in the NDR had given their
informed consent to participate in NDR (Paper IV). Answering the 27-item study-specific questionnaire (Paper II) and Swed-QOP questionnaire (Paper IV) was voluntary. All data were treated confidentially (Papers I-IV). The biochemical tests were conducted by experienced personnel; thus the studies were hardly likely to cause pain or discomfort to the participants (Papers II, IV).
Findings

Care providers’ view of implementing an empowerment programme (Paper I)

The main finding in this paper was conflicting roles. At the same time as the care providers started the transition from individual counselling in routine diabetes care to arrange group education at their centre, they needed to find their new role. There were many new factors to handle at the same time, and the care providers felt a need for support from their centre concerning the changed routines and approach.

The care providers were used to the traditional approach they had been applying in the individual counselling in routine diabetes care; empowerment was new to them. They understood the empowerment approach theoretically, but felt unaccustomed to it and needed time to grow into it. It was easy to fall back into their roles as experts who gave advice and recommendations to the patients. As experts, they felt secure - they knew what was best for the patient. They felt that becoming a facilitator who considered patients’ needs required time and training. As facilitators, they felt a need for support in their learning process in direct connection to the sessions.

Impact of the empowerment programme (Paper II)

No significant differences were found in the per protocol analyses in baseline values of patients’ characteristics (sex, occupation, marital status, age, diabetes duration, treatment) and outcome measures (confidence in diabetes knowledge, self-efficacy, satisfaction with daily life, BMI and HbA$_{1c}$) between the patients in the empowerment programme and those in individual counselling in routine diabetes care.

In the ITT analysis it was found that significantly ($p<0.05$) more patients in the empowerment programme were married/cohabitant compared to those in routine diabetes care.

At the one-year follow-up, the patients’ level of confidence in diabetes knowledge was significantly higher in the empowerment programme than that of the patients in the individual counselling in routine diabetes care ($p<0.05$). No statistically significant differences were found in self-efficacy, satisfaction with daily life, BMI or HbA$_{1c}$ between the patients in the em-
Patients’ experiences of participating in the programme (Paper III)

The patients’ experiences of education at their centre differed depending on whether they had participated in the empowerment programme or the individual counselling in routine diabetes care. The three main categories found that represented both groups were: relationship, learning and controlling the disease. The patients’ experiences differed within these main categories. Those in the empowerment programme experienced horizontal relationships, participatory learning and self-control. They experienced an open environment, sense of community and support from both the other participants and the programme facilitators. They talked about how the programme gave them the possibility to exchange experiences, and allowed them to evaluate and reflect on their experiences and learn more about their disease. Further, the programme helped them gain insight into their disease and to realize that they needed to change their behaviour. The patients in the individual counselling in routine diabetes care experienced vertical relationships, learning by compliance and external control. They said that it was the care providers who asked the questions, while it could happen that they went home with their questions unanswered. The care providers gave advice and recommendations, and nagged them if they did not follow the advice they had received. They were ambivalent as to whether they should change their behaviour because they did not feel any pain from a higher blood glucose level. In this setting, the care providers were seen as the experts who controlled the patients’ condition.

Patient education in Swedish primary health care (Paper IV)

In the individual counselling, 50% (n = 244) of the centres were found to be checklist-driven, 8% (n = 40) individualized the counselling based upon patients’ needs and 41% (n = 201) had not reported how they performed the counselling. A total of 22% (n = 105) of the centres reported that they arranged group education. Of these, 67% (n = 70) used pre-planned programmes, 9% (n = 9) individualized the programme to patients’ needs and 25% (n = 26) had not reported how they arranged the programme. The majority (91 – 98%) of centres reported that they set individual goals. A minority (23 – 36%) of the centres reported that patients were involved in the final decisions regarding their goal setting.
Individual goal setting was found to have an impact on patients’ possibilities to reach national treatment targets after adjustments were performed for organizational factors such as list size of centres and personnel resources. Setting individual goals was found to have an impact on patients’ possibilities to reach the treatment targets for HbA$_{1c}$, blood pressure, cholesterol and physical activity. Reaching the treatment target for HbA$_{1c}$ was related to those who set HbA$_{1c}$ goals ($R^2= 0.057$, $p = 0.034$), blood pressure ($R^2= 0.044$, $p = 0.007$) and cholesterol ($R^2 = 0.021$, $p = 0.002$) to lipid goals, and physical activity to HbA$_{1c}$ goals ($R^2 = 0.022$, $p = 0.051$).
Discussion

In this thesis, different aspects of patient education for people with type 2 diabetes in primary health care have been evaluated. The empowerment approach applied in a primary health care setting in central Sweden has highlighted the difficulties involved when introducing a new approach. The findings showed that care providers needed support during the learning process involved in implementing the empowerment programme. On the other hand, patients’ level of confidence with regard to diabetes knowledge had increased after they had taken part in the new programme. However, this did not influence their glycaemic control. Patients who participated in the programme experienced self-control, while those in individual counselling in routine diabetes care experienced external control. The findings indicate that nationwide patient education is generally provided in checklist-driven individual counselling and that few centres arrange group education programmes. The counselling is seldom individualized based upon patients’ needs, and patients are not involved in the final decisions regarding their goals. Setting individual goals, however, was found to have an impact on patients’ possibilities to reach national treatment targets.

The care providers who implemented the programme experienced conflicting roles when applying the empowerment approach. They were acquainted with their role as experts in individual counselling in routine diabetes care, and knew very well how to inform patients. The new role as facilitator implied a need for support in the learning process. This is in line with what other studies have reported – that care providers need time to implement a new approach or method (105, 106). It has also been found that it is easier to place learning in a context if you have knowledge about the issue you are learning (95). The conflicting roles the care providers experienced had their origin in the fact that they had been used to being the experts during all their years of working in health care. When participating in the programme, they struggled to discard their old “backpack” to begin applying a new approach in their encounter with the patient. This is in accordance with adult learning theories. Moxnes (94) asserted that adults need to “un-learn” to get rid of old knowledge in order to be able to attain new knowledge. In adult learning experiences, reflection and evaluation are considered important for changing one’s frame of reference (92-94). Learning is considered to involve behavioural change (94). The findings indicate that the care providers had changed
their behaviour, but that their learning might have been facilitated if they had received support from the supervisor in direct connection to the sessions. In the summary of type 2 diabetes educational intervention studies in Europe (Table II), two studies reported that they had provided continual feedback to the responsible care providers/pharmacists during the study (77, 83). These two studies showed significant impact on patients’ glycaemic control at two- (83) and six-year follow-up (77) compared to the control group. Significant findings were also reported when the researchers themselves had been the teachers (82, 84, 87). This indicates how difficult it might be to transfer the intended intervention to other professionals.

The empowerment programme improved patients’ level of confidence in their diabetes knowledge compared with those who had received individual counselling in routine diabetes care. However, the programme did not have any impact on the patients’ glycaemic control. Other European type 2 diabetes educational intervention studies have found significant impact on patients’ glycaemic control compared with the control group shown in Table II. However, there were several differences between our intervention and those in the summary. One was the follow-up time. It seems that interventions with long-term follow-up (5-6 years) have significant impact on patients’ glycaemic control (77, 82, 87). Two of these studies have had regular encounters between the care providers and patients every third month (77, 82).

Of the six studies (79, 83-86, 88) that reported follow-up time in accordance with our one-year follow-up study, three (84-86) reported significant improvement in patients’ glycaemic control compared to the control group. The differences between our study and these three studies were the personnel responsible for the programme (84-86), the care providers’ training prior to the programme (84-86), the amount of time provided in the intervention (85, 86), the theory underlying the programme (86), and where the studies were conducted (84, 85).

Of the nine studies in Table II, three were performed in a primary health care setting (77, 87, 88). Providing individual goal setting every third month was found to have an impact on patients’ glycaemic control at six-year follow-up (77). Having the researcher as moderator in ten 2-h group sessions was also found to have an impact on patients’ glycaemic control at long-term follow-up (5 years) (87), while no effect was found after one day or two half-day group sessions at one-year follow-up (88).

The summary indicated that regular encounters between care providers and patients over a longer period of time have an impact on patients’ glycaemic control. This finding is in accordance with the findings of Norris and Loveman et al. (75, 76). They found that the amount of contact time and/or contacts over longer intervals between care providers and patients have an impact on patients’ glycaemic control. Therefore, with the knowledge we have today we should have planned for more encounters between the care
providers and patients for a longer period of time in our intervention. Most people with type 2 diabetes receive their care and education in primary health care for that reason the intervention ought to be performed in this setting with their ordinary care providers so that the findings can be replicated and generalized.

To increase our understanding of the process that occurred among the patients who had participated in the empowerment programme, we performed the interview study with patients who had participated in the one-year follow-up study. The programme was based on the empowerment philosophy and adult learning principles. These principles were in accordance with Moxnes and Knowles’ (92-94) view of adult learning. Patients were encouraged to decide what behavioural changes they needed to undertake in their self-care and to reflect on and evaluate their experiences to be able to change their frame of reference. Freire (67) proposed critical thinking through group dialogue, in which everyone participates as equals, including the teacher, to create social knowledge. He asserted that “without dialogue there is no communication and without communication there can be no true education” (67, p. 92-93). Further, he considered that as a teacher you need to have “trust in people and their creative power” (67, p. 75). Knowles (92) asserted that adults often want to apply new knowledge immediately. Our weekly programme was arranged to facilitate patients’ ability to apply their new knowledge in their self-care. The design of the programme might have facilitated patients’ possibilities to begin understanding their condition and how to manage it in their daily life.

The patients in the individual counselling reported a relationship based on compliance and external control. Their description of the education in the individual counselling seems to be in accordance to what Freire referred to as “banking education” or one-way communication (67). We interpreted the patients’ descriptions of their learning as compliance. The concept of compliance has been seen within medicine as patients having to follow the advice given to them by their care providers (107, 108). However, this view of the concept might not be in accordance with Sackett and Haynes’ intention (56). Their aim regarding this concept was a non-judgmental alternative to the previously used concept of “recalcitrance”. It has been discussed that the concept of compliance should be replaced with that of “adherence”, which has been considered to be less authoritative. However, Sackett and Haynes saw these two concepts as interchangeable (56, 107), stating that an agreement between care providers and patients is necessary before any attempts can be made to change patients’ behaviour (56). Anderson and Funnell asserted that “eliminating the concept of compliance and adherence makes it possible to discover and actualize the patients’ responsibility for their diabetes self-management”. It would be a “win-win collaboration among equals” (109, p. 603). In later years another concept, “concordance”, has been dis-
discussed as a replacement for “compliance” and “adherence”. This concept includes negotiation between equals, openness in the relationship and a therapeutic alliance between care providers and patients (110). This concept seems to be in accordance with the empowerment philosophy and might contribute to a change in relationship between care providers and patients.

The nationwide survey was conducted to give us knowledge of how patient education is arranged in Swedish primary health care and whether it has an impact on patients’ possibilities to reach national treatment targets. The findings from the survey highlighted the fact that patient education seems to be traditional and pre-planned, and little consideration was taken regarding patients’ individual needs or their possibilities to set their own goals. In general, the patient is provided education in individual counselling and a minority of patients were offered participation in group education programmes. However, the evidence is conflicting regarding whether the education ought to be provided in a group setting or as individual counselling (74, 75). In their systematic review, Deakin et al. (74) found that group education improved patients’ metabolic control compared to routine treatment, while Norris et al. (75) did not find differences in patients’ glycaemic control if the education had been delivered in a group or in individual counselling. It has been found cost effective, however, to provide the same amount of information to patients in a group than in individual counselling (111). In the summary of the educational intervention studies performed in Europe (Table II), it was found that most of the interventions have been performed as group education (79, 82-85, 87, 88). Only two had been performed as individual counselling (77, 78), one in a primary health care setting (77). In this intervention it was found that individual goal setting every third month improved patients’ glycaemic control, compared to patients in routine diabetes care.

In our nationwide survey we found that individual goal setting has an impact on patients’ possibilities to reach national treatment targets. However, there is still a gap between our findings in the national survey and the actual treatment targets at the time of this study (40), and the gap is even greater regarding the new treatment targets for people with type 2 diabetes (41). However, based on the findings in UKPDS (31, 34, 35) and the Steno 2-Study (32, 43, 44) it seems necessary to support patients in their struggle to maintain or reach the new treatment targets. The report from the ACCORD study directed our attention to the importance of individualizing the treatment for each person (47, 48). Registration of data in the NDR has facilitated the assessment of the quality in diabetes care. Twelve years after the implementation of the register most centres (80%) participate, but only half of all diabetes patients are registered in the NDR (52). In the UK, on the other hand, most patients are reported to the QOF. However, the aim of their register was not only to evaluate the quality of diabetes care but to create a pay-for-performance system (50, 51). Our understanding of how we could im-
prove the quality in diabetes care would improve if more information were reported to the NDR, e.g. patients’ socioeconomic status, how patient education is provided, patients’ experiences of living with the disease, number of contacts per year and organizational factors.

The findings in this thesis show that implementation of the empowerment approach takes time and requires effort from care providers to make this change. It might be that implementation of the empowerment approach would have been facilitated if it had been performed as individual counselling in routine diabetes care. More patients would also have been able to take advantage of the approach, since few are offered participation in a group education programme in primary health care. It needs to be discussed whether it is realistic to implement an approach in a group education programme in primary health care when the only significant finding was that patients’ level of confidence in diabetes knowledge increased. On the other hand, the patients in the individual counselling in routine diabetes care asked for more knowledge about their disease. It seems that a change in approach is needed for patients with chronic disease. Which approach we apply is not a question of patients’ glycaemic control but one of respect for the individual to be listened to. It is the patient’s right to choose whether he/she wants to have responsibility and control over the condition or whether he/she wants the care providers to control the disease, because living with a chronic disease is not a static condition. Things happen in life and it can sometimes feel reassuring to have someone who tells you what to do and who keeps watch over your disease, while at other times you want to control your condition yourself.

Involving our patients more in their self-care, using goal-setting and having more than one or two encounters per year between care providers and patients might improve the quality in diabetes care. Whether these encounters are provided in individual counselling or a group education programme can be a question for the organization in primary health care.
Methodological considerations

Different qualitative and quantitative study designs were used in this thesis. Focus-group interviews (Paper I), randomized controlled trial (Paper II), individual interviews (Paper III) and a national survey (Paper IV) were conducted.

The strength of Paper I was that the moderator who performed the focus-group interviews did not have any relationship with the participants. The moderator was from LUCD and had not been involved in the participants’ training in becoming facilitators in the empowerment programme or in the programme. One of the assistants (the author) who participated as an observer during the focus-group interviews was, on the other hand, known to the participants. This assistant was not involved in the discussions during the interviews, but it cannot be dismissed that her presence may have had an impact on the participants’ ability to feel that they could speak freely. The author who performed the individual interviews had no relationship with the patients and they met each other only once, which might have facilitated patients’ ability to speak freely.

The focus-group interviews were performed to ensure that the care providers had applied the empowerment approach in the intervention in Paper II, because barriers to applying a new method or approach had been reported (70, 89-91); these barriers have been considered to influence the outcome of the intervention (91). Data from the focus-group interviews indicated a conflict in roles among the care providers in changing from being the expert to a facilitator in the empowerment programme. However, the care providers were aware that they had been the expert/superior in the individual counselling in routine diabetes care. According to Freire (67), this is the first stage in the transformation of power – being aware of your acting as oppressor/superior. Freire asserted that as long as you are unaware of your condition as oppressor/superior you continue to have control over others. The findings in data from the individual interviews with the patients who had participated in the programme strengthen the fact that the care providers had applied the empowerment approach in the intervention in Paper II. The patients experienced a relationship between equals, participatory learning and increased self-control. Rappaport states that for some individuals, control in the empowerment process can mean a sense of control, while for others it can lead to real control (68). Another strength of Paper II was the presence of a comparison group to control for bias, since the care providers who were facilitators in the empowerment programme may have been in contact with patients who had participated in the individual counselling in routine diabetes care. No statistically significant differences were found between the control and the comparison groups. However, due to the small sample size in the groups, we are not able to exclude the possibility of contamination. Further, the strict study criteria might have excluded patients with special needs from
participating in the empowerment programme. It is also possible that the care provider at each centre might have performed a selection of patients that was broader than the study criteria. However, the study design controls for systematic bias - the effect will on the average be the same in both groups when the patients are randomized to either of the two groups. The statistical power was lower than planned, which might have had an impact on the findings. Generalization in Paper II is limited due to the strict study criteria and the limited catchment area.

The findings from Paper IV, on the other hand, can be considered representative of how patient education in diabetes is arranged in Swedish primary health care, because of the widespread geographical coverage of the centres and the great number of patients included in the study. However, a limitation is that we have not been able to adjust for socio-economic factors. Low socio-economic factors have been found to affect the risk of morbidity and mortality in diabetes (112). Reason is that individuals’ socio-economic factors are not reported to the NDR, and using data on an area level is not convenient because in many county councils in Sweden, patients are able to choose whether they want to be listed with a GP or PHCCs in their catchment area or elsewhere. Furthermore, the PHCCs’ catchment areas often contain a mixture of socio-economic status.

A drop-out analysis was not considered possible in either Paper II or Paper IV. Due to ethical considerations and out of respect for the patients’ and the centres’ decisions not to participate, no further questions about characteristics were posed to those who declined participation. The data reported to the NDR from the centres have not been systematically tested, which might have had an impact on the results. However, all data reported have been validated by filtering extreme values (53).
Conclusions

- Implementation of the empowerment approach takes time and requires effort from the care providers. It is not enough to participate in a workshop to be able to master the new approach; care providers also need support when they implement the approach in clinical practice.

- Patients’ level of confidence in diabetes knowledge increased after they had participated in the empowerment programme. However, this did not influence their glycaemic control.

- The patients in the programme were given time between sessions to experience, reflect on and evaluate the behavioural change they needed to undertake in their self-care. This might have contributed to their experiences of self-control. The patients in the individual counselling met their care providers once or twice per year, and these meetings did not give them the same opportunity to begin to understand their condition as the patients in the programme had.

- The counselling in Swedish primary health care is seldom individualized based upon patients’ needs, and patients are not involved in the final decisions regarding their goals. Setting individual goals, however, was found to facilitate patients’ possibilities to reach national treatment targets for HbA$_1c$, blood pressure, cholesterol and physical activity.
Gunnar was 63 years old when his type 2 diabetes was detected ten years ago at a general health check-up at his primary health care centre. He was informed about the disease and given advice and recommendations about food intake and regular exercise. Gunnar was a compliant patient and followed the advice and recommendations given to him in the individual counselling in routine diabetes care. Gunnar appreciated the fact that the care providers wanted to perform yearly check-ups of his condition. He was satisfied with his care until his GP suggested that he should begin insulin treatment – he wanted instead to continue to treat his diabetes with diet, exercise and OHA. His GP proposed that he could participate in the hospital’s one-week programme for patients with type 2 diabetes to consider the suggested change of treatment and give him the possibility to learn more about his disease. Gunnar was referred to the one-week programme, which contributed to his comprehension of the fact that decreases in insulin secretion are a natural development when you have type 2 diabetes. He then realized that he needed to take insulin. Further, he also realized that the yearly medical check-ups at his centre were not for the GP and DSN to keep control of his condition but that they were rather a tool for himself to have control of his disease.

If Gunnar had been able to discuss his diabetes during regular encounters with his care providers in the individual counselling and been given time for experiences, reflection and evaluation, he would not have needed to live with his condition for ten years without understanding it, and his GP would not have needed to tell him it was time to supplement with insulin. Gunnar could have said to his GP: “I’m doing as well as I can concerning diet and exercise, but I cannot do any more. If I do more it will have an impact on my quality of life. You have to support me in my medical treatment because I am not satisfied with my blood glucose levels”.

Epilogue
Appendix

Enkät till personer med typ 2 diabetes  Datum:__________  Nr:__________

1. Kön:  Man ☐  Kvinnan ☐
2. Din ålder: ________år
3. Familjesituation:  Gift / Sambo ☐
                      Ensamboende ☐
4. Sysselsättning:  Arbetar ☐  Pensionär ☐
                    Arbetslös ☐  Sjukpensionär ☐
                    Något annat, vad? ____________________________
5. Hur många år har du haft diabetes? ________år

Hur upplever du att dina kunskaper är om:

Markera med ett kryss på linjen

<table>
<thead>
<tr>
<th></th>
<th>låg nivå</th>
<th>hög nivå</th>
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</thead>
<tbody>
<tr>
<td>6. Sjukdomen</td>
<td>1__________________________</td>
<td>10</td>
</tr>
<tr>
<td>7. Behandlingen</td>
<td>1__________________________</td>
<td>10</td>
</tr>
<tr>
<td>8. Självtester (blodsocker)</td>
<td>1__________________________</td>
<td>10</td>
</tr>
<tr>
<td>9. Maten</td>
<td>1__________________________</td>
<td>10</td>
</tr>
<tr>
<td>10. Fotvård</td>
<td>1__________________________</td>
<td>10</td>
</tr>
<tr>
<td>11. Motion</td>
<td>1__________________________</td>
<td>10</td>
</tr>
<tr>
<td>12. Komplikationer till följd av sjukdomen</td>
<td>1__________________________</td>
<td>10</td>
</tr>
</tbody>
</table>
Hur klarar du egenvård vad beträffar följande:

**Markera med ett kryss på linjen**

<table>
<thead>
<tr>
<th>mycket dåligt</th>
<th>mycket bra</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. Ta dina diabetesmediciner på det sätt som doktorn orderat</td>
<td>1_________________________10</td>
</tr>
<tr>
<td>22. Välja mat som är ”bra” med tanke på diabetes</td>
<td>1_________________________10</td>
</tr>
<tr>
<td>23. Välja mat enligt tallriks- Modellen</td>
<td>1_________________________10</td>
</tr>
<tr>
<td>24. Nå en vikt som är bra för dig (om du har övervikt)</td>
<td>1_________________________10</td>
</tr>
<tr>
<td>25. Måta blodsockret i form av blodsockerkurvor – före frukost, före lunch, före middag, vid sänggående, samt nästa morgon (några ggr/månad)</td>
<td>1_________________________10</td>
</tr>
<tr>
<td>26. Använda resultat från egna blodsockerkontroller när du sköter din diabetes</td>
<td>1_________________________10</td>
</tr>
<tr>
<td>27. Sköta om dina fötter regelbundet (några ggr/vecka)</td>
<td>1_________________________10</td>
</tr>
<tr>
<td>28. Motionera regelbundet minst 30 minuter (några ggr/vecka)</td>
<td>1_________________________10</td>
</tr>
<tr>
<td>29. Reglera blodsockret med hjälp av mat</td>
<td>1_________________________10</td>
</tr>
<tr>
<td>30. Reglera blodsockret med hjälp av motion</td>
<td>1_________________________10</td>
</tr>
</tbody>
</table>
Hur ser du på följande frågor ur diabetesperspektiv?

### Var snäll och besvara samtliga frågor!

<table>
<thead>
<tr>
<th>Fråga</th>
<th>Väljigt nöjd</th>
<th>Missnöjd</th>
<th>Varken nöjd eller missnöjd</th>
<th>Nöjd</th>
<th>Väljligt missnöjd</th>
</tr>
</thead>
<tbody>
<tr>
<td>31. Hur nöjd är du med den behandling du har?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. Hur nöjd är du med dina matvanor?</td>
<td></td>
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</tr>
<tr>
<td>33. Hur nöjd är du med dina motionsvanor?</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>34. Hur nöjd är du med din förmåga att utföra dina dagliga aktiviteter?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>35. Hur nöjd är du med hur du ”sköter” din diabetes</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>36. Hur nöjd är du med det stöd som dina anhöriga ger dig i samband med din diabetes?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>37. Hur nöjd är du med det stöd som dina vänner ger dig i samband med din diabetes?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38. Hur nöjd är du med din sömn?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>39. Hur nöjd är du med ditt sexliv?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40. Hur nöjd är du med dig själv?</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Har du andra kroniska/långvariga sjukdomar? ____________________________

__________________________________________

Plats för egna kommentarer: ____________________________

__________________________________________

Trots att patientutbildning anses vara en naturlig del i diabetesvärdem saknas det kunskap om hur den bedrivs i primärvården i Sverige och hur den påverkar patienternas möjligheter att nå nationella behandlingsmål. Det övergripande syftet med föreliggande avhandling var därför att undersöka olika aspekter av patientutbildning för personer med typ 2 diabetes inom primärvården i Sverige. Delstudie I genomfördes för att få en insikt i och förståelse för allmänlakarsspecialisters och diabetessjuksköterskors syn på implementering av gruppendervisning med empowerment som förhållningssätt (empowermentprogram) och möjligheter och hinder för dess implementering. I delstudie II utvärderades huruvida empowermentprogrammet jämfört med gängse diabetesvård påverkade patienternas tillit till sin diabetes-
kunskap, hanteringen av egenvården och tillfredsställelse med sitt dagliga liv samt BMI och glykemiska kontroll vid 1-årsuppföljning. Delstudie III genomfördes för att få en uppfattning om patienternas erfarenhet av de två olika undervisningsformerna. Syftet med delstudie IV var att beskriva hur patientutbildning bedrivs i primärvården i Sverige och att utvärdera om formerna för undervisningen och individuell målsättning inverkar på patienternas möjlighet att nå nationella behandlingsmål avseende HbA1c, BMI, blodtryck, kolesterol och fysiska aktivitet.

Data för de tre första delarbetena har samlats in inom primärvården i Västerås och för det fjärde delarbetet skedde datainsamlingen i hela primärvården i landet. Både kvalitativa och kvantitativa metoder har använts vid datainsamlingen. Fokusgruppsintervju valdes som metod för att få vårdpersonalens syn på implementering av empowermentprogrammet. En randomiserad kontrollerad studie genomfördes för att utvärdera vilken effekt programmet hade för patienter med typ 2 diabetes jämfört med den gängse diabetesvården. För att fånga patienternas erfarenheter av de två olika undervisningsformerna genomfördes individuella intervjuer med patienterna som deltagit i den randomiserade studien. En nationell kartläggning genomfördes där data samlades in i form av ett formulär med frågor om bl a patientutbildning, resurser och organisation som skickades till alla vårdcentraler i landet och genom NDR. Detta för att få en beskrivning och utvärdering av patientutbildningen i primärvården i Sverige.

I delstudie I deltog fem allmänläkarspecialister och 11 diabetessjuksköterskor från sex vårdcentraler som hade implementerat empowermentprogram. Före fokusgruppsintervjuernas genomförande hade de deltagit i en två dagars workshop om empowerment och varit handledare i två empowermentprogram. I delstudie II lottades 101 patienter från sju vårdcentraler till två grupper, 50 patienter till empowermentprogram (interventionsgrupp) och 51 patienter till gängse diabetesvården (kontrollgrupp). Patienterna i interventionsgruppen var 62.4 år och hade haft diabetes 6.5 år och patienterna i kontrollgruppen var 63.7 år och hade haft diabetes 6.7 år. I delstudie III deltog 28 patienter, 14 patienter från varje grupp av de patienter som deltagit i delstudie II. Patienterna i empowermentprogrammet var i medeltal 61.9 år och hade haft diabetes 5.8 år och de i den gängse diabetesvården var 64.9 år och hade haft sin diabetes 6.7 år. I den nationella kartläggningen inkluderades 485 vårdcentraler med 91 637 patienter. Patienterna som deltog var i genomsnitt 68 år och hade haft diabetes 8.6 år.

Huvudfyndet i delstudie I var att det existerade en rollkonflikt. Det var svårt för personalen att släppa ”den gamla ryggsäcken”. Det var enklare att bara tala om för patienten vad han eller hon skulle göra än att lyssna och låta patienten komma med egna lösningar. Personalen upplevde att det blev flera moment att fokusera på, eftersom de både skulle vara handledare för en grupp med patienter och också använda sig av ett nytt förhållningssätt. De ansåg att de hade behövt stöd vid implementeringen av förhållningssättet.
Effekterna av implementering av empowermentprogrammet i delstudie II visade att patienternas tillit till sin diabeteskunskap hade ökat efter att de deltagit i programmet, men den glykemiska kontrollen mätt med HbA1c förbättrades inte jämfört med kontrollgruppen. Inga statistiskt signifikanta skillnader kunde ses i de övrigavariablerna som mättes i delstudien.

Delstudie III visade att patienternas erfarenheter av de två undervisningsformerna skiljde sig beträffande: a) förhållandet mellan vårdgivare och patient, b) patientens möjlighet att lära sig om sin sjukdom och c) patientens möjlighet till sjukdomskontroll. I empowermentprogrammet upplevde patienterna att de kunde tala med sina handledare. De fick möjlighet att lära sig förstå vad diabetessjukdomen handlar om och de upplevde att de hade egenkontroll. I gängse diabetesvård fick patienterna råd om bra matvanor, att motionera regelbundet och att gå ner i vikt, däremot saknade de kunskap om sjukdomen och hur de skulle hantera dagliga situationer. Patienterna upplevde att personalen hade kontroll över deras sjukdom.

I delstudie IV framkom det att av de 485 vårdcentralerna använde 50% (n = 244) checklistor i den individuella undervisningen och 8% (n=40) individualiserade undervisningen utifrån patienternas behov. Totalt bedrev 22% (n=105) av vårdcentralerna gruppunkvisning som komplement till den individuella undervisningen. Majoriteten (91 - 98%) av vårdcentraler satte individuella mål för patienten medan en minoritet (23 - 36%) involverade patienten i själva målsättningen. Att sätta individuella mål visade sig påverka patienternas möjligheter att nå nationella behandlingsmål för HbA1c, blodtryck, kolesterol och fysisk aktivitet.

Resultaten av dessa studier visar att personalen skulle ha getts mera tid att med stöd av handledare träna empowerment som förhållningssätt. Det är också möjligt att det hade underlättat om implementeringen av empowerment som förhållningssätt hade skett i den individuella undervisningen i gängse diabetesvård. Det skulle också innebära att det kunde komma fler patienter till del eftersom alla patienter inte väljer att delta i gruppunkvisning. I denna avhandling fann vi inga signifikanta skillnader i glykemisk kontroll mellan patienterna som deltagit i empowermentprogrammet eller i gängse diabetesvård. Senare års forskning har däremot visat att det avgörande för resultatet av patientutbildning för personer med typ 2 diabetes är tiden som patient och vårdgivare möts. Om mer tid avsätta för uppföljningar oavsett om patienten deltar i grupp eller i individuella möten med sin vårdgivare i primärvården skulle detta kunna bidra till att inte bara deras glykemiska kontroll skulle kunna förbättras utan också påverka deras möjlighet att nå nationella behandlingsmål avseende HbA1c, BMI, blodtryck, kolesterol och fysiska aktivitet. Data från fokusgruppsintervjuerna med personalen, intervjuerna med patienterna som deltog i programmet och utvärderingen av patientutbildningen i Sverige tyder på att det behövs en utveckling av diabetesvården i primärvården så att hänsyn tas till varje persons individuella behov.
Acknowledgements

This work was carried out in the county council of Västmanland and in the whole of Swedish primary health care. I would like to express my sincere gratitude and appreciation to all the patients, diabetes specialist nurses, general practitioners and managers in primary health care for your participation in these studies and to everyone else who has been involved in the work underlying this thesis, with special thanks to the following people:

*Karin Wikblad*, my supervisor, who excellently and with never-ending patience has guided me through the research project. Thank you for sharing your broad scientific experience. You have always given constructive comments and advice on my work.

*Bibbi Smide*, my co-supervisor, for your continuous guidance, never-ending support and help in creating a more nuanced language in the manuscripts.

*Marie-Louse Engström*, my co-supervisor, who has always been helpful and given me support and valuable advice when I have asked for it.

*Bengt Starrin*, my consultant-supervisor, for your enthusiastic guidance and for teaching me to focus on positive aspects and believe in my own capacity.

*Jerzy Leppert*, Head of the Centre for Clinical Research in Västerås, for providing the time and resources that made my research project possible.

At the Centre for Clinical Research in Västerås:
*Katarina Ringström, Gun Nyberg, Tony Wiklund* and *Maria Deltuva Karlsson*, for your help and support during these years with EndNote, Powerpoint, posters, data and practical things.

*Andreas Rosenblad* and *Kent Nilsson*, for your statistical advice. You have always been available for questions and discussions on the statistical methods and the data analyses.

*Leif Bergkvist*, for taking time for me when I have needed to discuss scientific problems.

*Rickard Sjöberg*, for your support and guidance during our visits in Camargue.
All PhD and doctoral students at the Centre for all the inspired discussions at the seminars and all the joy we have had together in Västerås as well as in Camargue.  
Tuula Wallsten, my dear friend and roommate at the Centre and in Camargue, for your encouragement and constructive advice. We have shared happiness and trouble, but most of all we have laughed together and enjoyed this creative environment.

At the Department of Medical Sciences, Diabetes Nursing Research, Uppsala University:
Anna Lindholm, Ulla Nygren and Ewa Billing, for the stimulating discussions at the seminars and the social events we have attended together.
Janet Leksell, for contributing to fruitful discussions at the seminars and for always being willing to share your knowledge as well as laughter.
Gunnel Viklund, for being a supportive colleague and giving me constructive comments and advice on my work.
Lillemor Fernström, for your friendship, engagement and encouragement during my doctoral studies.

Rolf Jansson, for making it possible to start my doctoral studies. You have contributed to this research project more than you can imagine.

Åke Tenerz, for your great support, encouragement and inspiration during all these years. I really appreciate that you always have been there for me.

Peter Tilly, for your co-operation, which made it possible for me to perform the studies in primary health care in the county council of Västmanland.

Bo Simonsson, my friend and colleague, for always taking time for me when I have needed to discuss my scientific problems. You have supported and encouraged me during these years.

Stefan Sörensen, for introducing me to the statistical world.

Susanne Hedberg, for always being supportive in searching for literature when needed.

Soffia Gudhjörnsdóttir, National Coordinator responsible for the NDR, for your engagement and support, which made it possible to carry out the national survey (Swed-QOP).

Leyla Nunez, Statistician at the NDR, for your patient works with the data.
Tomas Fritz, Swedish Association of Diabetology and Mona Andersson, Swedish Association of Nurses in Diabetes Care, for your co-operation in conducting with the national survey (Swed-QOP).

Maurice Devenney and Karen Williams, for revising the English text in Papers I and II.

Judith Rinker, for always giving me priority in your schedule when I have needed to revise the English text in Papers III and IV as well as the thesis, and for your patience with all my questions.

Marita and Leif Thors, my parents, for your support of my work. You have never complained in spite of my endless working when I have visited you.

Gun Thors, my dear sister, for being there for me when I have needed support and encouragement.

Last but absolutely not least, my wonderful family: Lasse, my husband, for all your love, support and patience during all these years. Sofia, Emma and Julia, our daughters, for supporting me even when I have spent many late hours at work. Thanks for all your help with data collection for the national survey (Swed-QOP).

I look forward to spending more time with you. You are the best. You are the sun in my life.

The studies have been supported by grants from the Swedish Diabetes Association and the Family Ernfors Fund.
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Acta Universitatis Upsaliensis

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