Teaching and Learning in Type 2 Diabetes

The Importance of Self-Perceived Roles in Disease Management

ANIKÓ VÉG
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Abstract


The major part of care in type 2 diabetes is in the hands of the patient so the focus of educational interventions should be on the person behind the disease. An experience-based group education programme that actively promotes participants’ reflection and understanding has been designed and implemented in cooperation with the Swedish Pharmacy.

The regression model presented in Paper I revealed the importance of self-perceived role in diabetes management. Blood glucose control two years after baseline was improved for participants who described themselves as having an active role in their treatment, compared to those taking on a passive or a compliant role.

Paper II described the resulting categories from content analysis of three open-ended questions about participants’ role, goal and support needs in diabetes management. The people taking care of diabetes most effectively and needing least support were called Disease Managers; those following the health professionals’ orders and depending on regular controls were categorised as Compliant, whereas the Disheartened had difficulties in achieving good metabolic control and often described both medical and social obstacles. These three self-management profiles were strongly correlated to metabolic outcomes.

In Paper III perceptions of diabetes management were reassessed: perceptions were only stable in approximately half of participants, thus providing evidence for a dynamic model of learning self-management in diabetes. The three self-management profiles still correlated with metabolic outcomes.

In paper IV the long-term metabolic outcome (HbA₁c) of the study population was investigated. Metabolic control was stable up to seven years following the intervention, in contrast to the metabolic deterioration often present in diabetes.

The main message of this thesis is that participants’ self-perceived role had a major influence on metabolic outcomes. Assessing self-management profiles both in diabetes and possibly other chronic conditions can help health care providers to tailor their educational efforts accordingly. Furthermore, this experience-based patient education programme outside the framework of routine diabetes care has the potential to stabilise metabolic control on the long run effectively.

Keywords: Typ 2 diabetes, HbA(1c), Self-perception, Disease Management, Experience-based group education, Reflective learning

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List of Papers

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


III  Vég, Anikó, Rosenqvist, Urban, Sarkadi, Anna: Variation of Patients’ Views on Type 2 Diabetes Management over Time. *Diabetic Medicine* (Accepted)

IV  Vég, A, Rosenqvist, U, Sarkadi, A: Long-term follow-up of participants from an experience-based group education program for type 2 diabetes (Manuscript)
Cover: Teamwork rowing © Scott Maxwell
The author purchased the picture on the Internet (http://www.fotolia.com)
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# Abbreviations

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<tr>
<td>HbA₁c</td>
<td>Haemoglobin A₁c</td>
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<tr>
<td>BMI</td>
<td>Body mass index</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<td>SPSS</td>
<td>Software package for data management</td>
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“I think I control my food and exercise, but the body still does not work with me. Despite all my efforts, I sometimes have too high values”

“It’s good if someone helps out with diet and exercise. A good doctor with whom you can discuss everything and be summoned for controls”

“Health care cannot stand by my side the whole time and influence my everyday life”

Thoughts about diabetes – participants’ voices from the group education programme
Introduction

The field of disease management – from a special educator’s point of view

Would you agree with the statement that there is already quite an impressive body of research about diabetes? If your answer is yes, you would be right. You would not, however, presume that everything is already known about diabetes management, would you? And again, you would be right!

Parallel to the significant advances in the medical treatment of diabetes, I believe that important new findings on diabetes management can be expected in the near future, from pedagogical, as well as from psychosocial (Peyrot, M. et al., 2005) frameworks. As we progress in the research of chronic illnesses, it is becoming ever more evident that if we fail to take into account the psychosocial background of patients and do not apply modern pedagogical methods, we will not achieve the results that would come up to our expectations in the field of care and self-care. This, otherwise, presupposes cooperation between patients and health professionals, just as cooperation is necessary between the learner and the educator. As the cover picture illustrates, by sharing our perceptions about how rowing feels, and understanding each other we can steer our boat in the right direction, and those just learning to row may understand, based on the new experiences, how to steer the boat themselves. This learning method, founded on an attitude of partnership from both sides, is valid in diabetes management, as well. However, a possibly effective way to reach the desired outcome is to place the patient in the centre of attention.

A definition of patient-centred care I am more and more willing to identify with emphasizes the individual’s needs and values more than earlier definitions have. This definition entails “providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions” (CoQoHC, 2001).

Although patient-centred care has been argued to be something necessary, something that has to be achieved for optimal treatment outcomes, the attitude of focusing on patients’ individual development in the context of
disease management has not become integrated into the majority of patient education programmes. From an educator’s point of view, it is inconceivable why patient-centeredness should not be self-evident. Following from what I was taught and had practiced as a special educator, it seems obvious that teaching has to be individual-oriented and specialised in order to fit the needs of learners with different skills. Adults and children with mental and/or physical disabilities show significant differences in their use of subsisting functions according to the nature and extent of their impairment. Practically, this meant that I, as well as other personnel in the rehabilitation team, was always prepared for differential and individual-based training programmes for the learner with special needs, even though the education/rehabilitation was carried out in a group session. All tasks required the detailed assessment and analysis of the existing functions in order to adapt the technical equipment to the individual needs.

Thus, placing the individual in the centre of attention, analysing his or her needs and abilities and tailoring training programmes to suit them were evident to me. Why is it then, I wondered, so difficult to develop and maintain such a view in the medical care of patients for chronic diseases?

Although I came to understand some important aspects of teaching and learning in diabetes, I never lost my respect for the complexity of diabetes management, which may be explained by the pervasive, life long and progressive nature of the disease. With all its requirements of daily self-care and existing risks of complications diabetes affects the whole health care apparatus, the patient’s social network and everyday life, as well. Therefore, treating and managing diabetes places demands on the individual, as well as on the society and the health care providers.

Because diabetes is an accelerating public health problem, it requires a well-structured and goal-oriented system working in cooperation with the person who has the disease. The patients are expected to be active and well-informed who are able to take care of themselves. A conflict can occur when there is incongruence between how care should work and how it works in reality. There are different theories and attempts at providing the best care for people with diabetes, but there is still an unanswered part of this area: how to enable people to make and maintain a change in their behaviour. I was not very surprised, but all the more enthusiastic, to find early on that the self-perceived role of individuals in disease management played a major role in explaining outcomes.

As an educator, my interest fits well into the pedagogical part of diabetes treatment. My intention with this thesis is to highlight some new viewpoints concerning the teaching and learning of self-management in chronic conditions, where the patient as an individual, as well as the medical and social aspects are unified. In the coming chapter I will present the aims of the thesis and describe the theories and models behind patient education and our group education programme in further detail.
Aims

The main goal of this thesis is to examine how an experience-based patient education programme affected the patients’ metabolic outcomes and to explore factors related to these outcomes.

Specific goals of the studies:

Paper I
- To find the factors that influence participants’ metabolic control
- To understand how self-management and metabolic control can be affected by intra- and interpersonal factors

Paper II
- To examine whether it is possible to determine participants’ self-management profiles using three open-ended questions about their self-perceived role in diabetes management
- To analyse whether such self-management profiles have any bearing on haemoglobin A1c levels
- To design a model to enhance our understanding of people’s views of their own role in self-management

Paper III
- To observe whether people’s attitudes towards diabetes management change over an extended period of time

Paper IV
- To explore how participants from an experience-based group education programme had succeeded in maintaining metabolic control over a longer period of time
Background

Diabetes: global burden and treatment goals

Diabetes is one of the most growing public health problems and causes major morbidity all over the world. The latest WHO estimate showed that at least 173 million people worldwide had diabetes in 2002. It is predicted that the current number will double by the year 2030 (King, H. et al., 1998). The global rise in diabetes (Bagust, A. et al., 2002; Motala, A. A. et al., 2003) will occur because of population ageing and growth, and because of increasing trends towards obesity, an unhealthy diet and sedentary lifestyles (Harris, M. et al., 1998).

Diabetes is a chronic condition characterized by raised blood glucose levels. It develops when the pancreas does not produce enough insulin or when the body cannot effectively use the insulin it produces. There are two main forms of diabetes: type 1 and type 2. In the case of type 1 diabetes, little or no insulin is being produced. People with type 2 diabetes do have insulin production but the body is not able to use insulin effectively. Type 2 diabetes constitutes 90% of the diabetes population.

The resulting hyperglycemia can cause serious damage in the nerves and blood vessels, the latter leading to macro- and microvascular complications. The heart, kidneys, eyes, and lower extremities are at especially elevated risk in diabetes. These complications can be reduced by a near normalization of the glucose level (Reichard, P. et al., 1993; The Diabetes Control and Complications Trial Research Group, 1993; United Kingdom Prospective Diabetes Study Group, 1998), this normalization being the ultimate focus of all diabetes treatment.

People with type 1 diabetes require daily injections of insulin, whereas people with type 2 diabetes sometimes manage their condition by simply taking some measures in changing their lifestyle. However, oral drugs are often required and sometimes additional insulin, as well, in order to achieve good metabolic control.

While people with type 1 diabetes may suffer from a variety of acute symptoms (excessive thirst and urination, weight loss for no reason, vision changes etc), people with type 2 diabetes have less obvious symptoms. Many have no symptoms at all and are diagnosed many years after the actual onset.
As a consequence, almost half of all people with diabetes are not aware of their chronic condition (WHO 2003), which results in the delayed onset of secondary preventive efforts to avoid later complications.

In Sweden, about 50,000 people are diagnosed with type 2 diabetes every year, with a prevalence of 4% or more (Farnkvist, L. M. et al., 2003).

Organisation of diabetes care in Sweden

In Sweden, the national guidelines follow the St. Vincent declaration, with the main purpose of reducing diabetes-related complications. According to these guidelines people who have diabetes mellitus should be supported by the health care system to receive effective, efficient and equivalent care (Swedish National Board of Health and Welfare, 1999). The declaration also states that in order to ensure appropriate patient influence in the treatment the same standards for individual care plans should be used in all parts of the country. This means a mutual responsibility for achieving a satisfactory diabetes treatment and preventive work. Furthermore, to ensure the adequate implementation of the national guidelines, both clinics and primary health care centres are encouraged to report to the National Diabetes Register where they can compare their clinical results with the national average.

In practice, diabetes care is organised at two levels: hospital outpatient clinics at departments of medicine and at the primary health care level, where the bulk of diabetes care takes place. Medical clinics treat persons with type 1 diabetes, as well as those who have more severe or complicated type 2 diabetes. Primary health care is responsible for providing a diabetes team consisting of a diabetes-trained specialist in family medicine, a diabetes nurse, as well as a dietician, foot therapist and sometimes a psychologist (Agardh, C.-D. et al., 2005). Patients see the physician at least once a year, whereas they often have more regular contact with the diabetes nurse. According to the current philosophy of care, patients are expected to take an active role in their self-care and participate in the decision-making process.

Thus, the guidelines and the national standards for diabetes management are clearly formulated, but there is still a gap between what should be achieved and what reality presents (Eliasson, B. et al., 2005). Improving diabetes care is a complex task that needs to be tackled from several different angels. So far, I have primarily focused on the educational aspects, and in the following, I will go on to present relevant educational and behavioural theories in the treatment of chronic diseases.
Theoretical framework

The mainstream development of theories of how people think and act in relation to their chronic conditions could be divided into those looking at health behaviour and its correlates, such as health beliefs, motivation and coping-strategies and those analysing patient’s perception and understanding of the disease. A model, working on patient’s understanding is presented separately showing a new way of teaching disease management.

Models of behaviour in chronic diseases

In the literature three main types of health related behaviour have been distinguished and used as the cornerstones of health belief models: 1. health behaviour involves activities by a person for preserving and improving health, for example wearing seat belts; 2. illness behaviour includes all actions for seeking help and information for potential problems, e.g. asking friends who are familiar with health care; and 3. sick role behaviour deals with persons who have been diagnosed with an illness and take actions in order to restore their health (Bernard Larry, C. et al., 1994).

The Health Belief Model was developed by a group of cognitive and social psychologists in the late 60s (Rankin Sally H et al., 2001). The model analyses patients’ decision-making and can be used to promote behavioural change processes. Further models based upon this model for promoting health came along, such as the Health Promotion Models and the Self-Regulation Model among others, with subtle differences in their way of understanding motivation. Another model often referred to in many research studies is Prochaska’s trastheoretical model of behaviour change, which is based on estimating patient’s motivation and readiness for change. The stages of change predict the person’s current status of readiness for taking action. These stages are the precontemplation, contemplation, preparation, action and maintenance phases (Prochaska, J. O. et al., 1997).

There are further strategies, which devote more attention to the psychosocial and interpersonal factors in patients’ learning mechanisms, namely the coping strategies (Gillibrand, W. et al., 2001; Heim, E., 1995), which are influenced by how a person appraises the meaning of the illness and the received social support (Downe-Wamboldt, B. et al., 2006).

Self-efficacy was a determinant in social cognitive theories (Bandura, A., 2004) and describes person’s belief in his or her own ability to achieve a
desired goal. In patient education interventions self-efficacy involves those interpersonal factors reinforcing patient confidence, which, through behavioural changes, may lead to the desired health outcome. Kate Lorig et al. pointed out the importance of self-efficacy in the education of self-management for persons with rheumatic disease. Lorig operationalises self-management as more than self-care and patient education in the traditional sense; a concentration of knowledge and skills where the positive changes of self-efficacy make the improvement of the health status possible (Lorig, K. et al., 2003).

Mirroring the increased emphasis on actively involving patients in the decision-making process concerning chronic illnesses, the concepts of patient empowerment and patient-centred care have been developed (Funnell, M. M., 2004; Funnell, M. M. et al., 2003). The introduction of the term patient empowerment in the 70s established a new way of thinking, presenting a possibility for a better dialogue between patients and health care providers and also more responsibility to, and involvement of, patients (Anderson, R. M. et al., 1991; Levin, L., 1981). Patient empowerment can not actually be termed an educational effort because of its lack of pedagogical principles: patient empowerment does not struggle to work on learning and understanding. However, this approach is useful in assisting chronically ill patients to become partners in treatment: empowerment can thus be both the means and goal of interventions in clinical practice.

The cognitive, behavioural and emotional factors in maintaining a successful self-management act synergistically (Barlow, J. et al., 2002; Bourbeau, J. et al., 2004), and understanding these dynamics is essential in the design and practice of patient education.

Patient education in diabetes
In diabetes the main aim of the education is to create as much normality and stability in blood glucose levels (Deakin, T. et al., 2005) as possible in order to avoid complications, while being constantly confronted with new situations and challenges.

Living well with the disease can be achieved by having control over blood glucose regulation. This is the key outcome of health for people with diabetes. However, most of the educational programmes and models (Newman, P. S. et al., 2004) only achieve a short-term improvement of the metabolic control, measured by HbA1c (Brown, S., 1992; Cooper, H. C. et al., 2003; Norris, S. et al., 2002; Reichard, P. et al., 1993). There is disagreement as to how to provide diabetes education in order to attain the best possible result over a longer period (Norris, S. et al., 2002).

Patient education is considered to be an evident part of the treatment of chronic illnesses (Wagner, E. et al., 1996). However, the focus and target of
patient education has shifted in the last few decades. Nowadays the educational approach is more proactive and focuses on the patients’ everyday experiences of living with a disease, as compared to earlier models of care which were rather information-based. Today we realise that knowledge is not enough to maintain the lifestyle and behavioural changes that a chronic condition requires (Grey, M. et al., 2004; Mühlhauser, I. et al., 2000; Mühlhauser, I. et al., 2002). Instead, as Mühlhauser also points out, the importance of increasing patient autonomy and independency in disease management is emphasized and contrasted to traditional care, which strived to increase patients’ compliance (Mühlhauser, I., Berger, M., 2000).

Patient education is an ongoing process, and it influences patients’ behaviour, knowledge, skills and attitude towards improving their health. In modern terms, patient education interventions are considered to aim at assisting patients to interpret and integrate the received information into their everyday practices (Rankin Sally H D, S. K., 2001).

To find the most effective patient education for elderly people we should take a closer look at how adults learn and what their specific educational needs are.

Adults’ learning

Adult education has an extensive literature and has developed much since the late 1980s. The increased demand for higher education for the older generation has initiated mass education of people with different social backgrounds in the communities of the United Kingdom (Jarvis Peter et al., 2003). Experiences have shown that adults are self-motivated and highly self-determined in learning. Adult education is not compulsory in nature and, therefore, the learning situation can be described by three categories: people being goal, activity or learning oriented, the common key concept in all of these typologies being motivation.

The term of andragogy, i.e. how adults learn and how they are to be motivated to learn was introduced by Malcolm Knowles. His didactic principles are based on independent and self-directed learning including previous personal experiences and opportunities for reflection (Kaufman, D. M., 2003). One of the important ideas of Knowles’ theory is the learners’ involvement in the planning of their studies. This ‘learning contract’ should be rooted in the individuals’ learning needs, strategies and should, thereby, determine the learning objectives and resources. This development is considered to be ongoing throughout a person’s lifetime. Personal growth and social changes are significant terms in the development of self-directed learning, which has been described as a kind of lifelong learning. This means that education is continued after school with no end point, and a person has
to find a way to put the obtained knowledge into practice (Jarvis Peter et al., 2003).

Adults have more internal than external motivators, and they are more ready to learn as compared to school students (Newman, P. et al., 2002). Furthermore, in adults’ learning the emotional and social contexts play a major role. According to social learning theories socialisation, culture, language and communication influence what and how we learn. In contrast to this, behaviourist and cognitionist theories have underlined psychological and human development in the learning process.

It is not only the learner who has a key role in the learning process, but the educator, as well. The educators’ role in self-directed learning theories is to facilitate and enable, as opposed to using didactic principles and being an instructor. Emphasizing the practical implications of the learning objectives and showing flexibility in shifting between different educational roles are therefore important elements of being an educator for adults. However, adults can also learn without a teacher, with the aid of self-actualisation and autonomy in the learning process. It is, however, agreed that group training in e.g. diabetes is as efficient as individual training, if not more effective, and that educators who are not physicians or nurses may well be of use in the process (Brown, S., 1992; Norris, S. et al., 2002).

A new way of teaching and learning diabetes self-management

Not only what and how we teach, but also how people learn self-management is an important field in the study of educational interventions for chronic illnesses.

With experiences in health care and medical treatment, our research team has worked for a long time with the issue of how to support people with type 2 diabetes in their self-care (Rosenqvist, U., 2001; Sarkadi, A., 2001), and investigated how patients understand (Holmstrom, I. et al., 2005) and learn to manage diabetes (Saleh Stattin, N., 2001).

However, people with type 2 diabetes are often unaware of the connection between diabetes and its complications, such as high blood pressure, and do not recognise the increased risk of these complications (Stewart, J. et al., 2005). Educational programmes need to make an effort to help people understand the meaning of treatment.

The patient-guided and experience-based group education model presented in this thesis was based on theories about learners’ understanding. The central assumption guiding this educational development was that the way people understand certain phenomena in their lives, will influence the way they act in relation to that phenomenon (Marton, F. et al., 1997).
Jan Theman (Theman, J. et al., 1991) was an educator from Ferenc Marton’s group, who developed a method that made it possible to change persons’ understanding and the way they handled the phenomenon. To explore patients’ understanding Theman combined phenomenography and motivational interviewing (Rosenqvist, U. et al., 1995) using ‘what’ and ‘how’ questions to focus patients’ in-depth understanding. Based on the work of Theman and Ann-Christine Johnsson (Jonsson, A., 1995), who used in-depth interviews to understand how persons with diabetes learn self-management, an educational programme package was designed. The idea of propagating the programme on a national level became reality (Rosenqvist, U. et al., 1995) using the framework of the National Corporation of Swedish Pharmacies.

To emphasize the self-determined nature of learning in these groups, the form of the programme was termed “study circles”, referring to a prevalent form of adult education in Sweden where a group of people decide to gain in-depth knowledge about an area and meet regularly with or without a leader (Byström, J., 1983).

The programme, as its name “Living well with diabetes” suggests, aimed at enabling people to gain the necessary knowledge, skills and experience to deal with both the medical management and the daily routine of living with diabetes. The strategy of the programme was to promote patients’ self-management skills by their own experiences, and involved the testing of different foods, checking blood glucose levels and analysing how the measurements have been affected by the change in medications and lifestyle.

A calculation of cost-effectiveness indicated that the programme was suitable for mass education (Tennvall, G. et al., 1997). Active learning and understanding was promoted by using representative games and educational tools. A book helping them to see, for example, what was happening to their blood glucose levels, when they tried different regimes. An important pedagogical principle was the ‘try and see’ method with the ever repeated monitoring of blood glucose levels to determine influences of diet and exercise. These experiences and reflections in the group helped group leaders identify each person’s place in the trajectory of understanding.

The intervention was tested and proved feasible for mass education (Sarkadi, A. et al., 2000), and also had positive effects on participants’ metabolic control, as described in a randomized controlled trial (Sarkadi, A. et al., 2004).
Materials and methods

I will begin this chapter with a detailed description of the intervention and the data collection as these provided the background to all of my papers. It is also important to keep in mind that the same method, i.e. the combination of qualitative and quantitative approaches, was used at every stage of the data analyses. In connection to this, at the end of this chapter I will discuss some methodological questions which appeared in relation to the participation in the intervention and the method used.

The intervention

In the 1990s Rosenqvist and co-workers initiated a new model for educating people with type 2 diabetes in Sweden (Rosenqvist, U. et al., 1995). This approach, taking the form of study circles, became a nation-wide group education programme (Sarkadi, A. Rosenqvist, U., 2000).

The programme was announced by flyers and information sheets at different pharmacies, at GP offices and in local newspapers. Participants were self-referred and the criterion to join a group was being diagnosed with type 2 diabetes. The groups consisted of 8-12 people in average who, over the course of one year, met once a month for three hours during an afternoon session. The ethnicity of the participants was Caucasian.

The group leaders were pharmacists who participated in a three-day long training session to learn more about the treatment, the complications and the psychosocial aspects of diabetes. Additionally, a diabetes nurse specialist provided professional help at the first two meetings. The programme began with a day-long meeting of which the main goal was to create a common basis and a feeling of companionship by preparing food together.

Different educational resources were available to promote participants’ understanding of diabetes management. The support materials were a video, a cook book and a handbook for managing diabetes and a change in lifestyle. A diary for each participant was also followed during the intervention. A symbolic social game of rowing, in which a person had to make a decision in order to gain control over the boat was intentioned to facilitate participants’ self-reflection and understanding of how to manage diabetes. Rowing a boat was in fact used as a metaphor throughout the programme to illustrate the challenges of diabetes management. A rowboat can be rickety (initial
instability of blood glucose levels), one sits with the destination behind one’s back (unclear treatment goals) and it takes training and experience to be able to row without having to turn (checking the blood glucose) all the time.

The group sessions also had a fundamental practical purpose of improving patients’ skills in self-monitoring by estimating and testing blood glucose levels, and decreasing blood glucose levels by way of exercise and choosing appropriate foods. Moreover, the group members also had discussions about the consequences of changes in diet, medication or exercise, based on their own experiences they had registered between the group meetings. The key feature of the group sessions lay in the possibility of free reflection. Solving problems and answering questions was promoted by the participants’ own reflections and/or by their interaction with each other, all of them being there with the same diagnosis. Every meeting was adjusted to the individuals’ needs of reflection and asking questions and, in doing so, participants had possibilities to influence and steer the sessions (Rosenqvist, U. et al., 1995). Group settings have shown to be particularly effective because they add motivation, experience and peer identification.

Our expectation from this form of patient education was that participants’ understanding of diabetes and its management would improve, and would thereby lead to a better metabolic control.

The research programme at Uppsala University started as a pilot study (Sarkadi, A. et al., 1999), and was later tested in a randomised controlled trial to see whether the education had an impact on participants’ metabolic control (Sarkadi, A. Rosenqvist, U., 2004). Patients from the control group (N=38) also received questionnaires and took blood tests during the period of randomisation. After completing the randomised study, control patients were also invited to participate in a study circle.

In cooperation with the Swedish pharmacies the concept of the study circle became an ongoing project for educating people with diabetes at the local pharmacies from 1996. The dissemination of the programme was introduced nearly at the same time as the randomisation. The study circle programme ran for eight years, until 2005, as a supplement to routine diabetes care. Overall, 60 groups were initiated at 18 locations in the country.

This thesis presents the results from the period after randomisation. The figures below (Figure 1a&b) illustrate the history of the intervention and the number of initiated study circles during the investigated period.
Figure 1a) above: Procedure of the study circle programme between 1996-2005,
b) below: Number of study circles started during the intervention 1997-2004.
Data collection

Data were collected all throughout the education programme. The first analysis was performed in 2003, and the second set was processed in 2005. All of the participants had received the blood tests and the two year follow-up survey, distributed 24 months after the baseline. Papers I & II are based on the first analysis of the collected data with answers from a total of 259 participants. The third paper presents the long-term follow-up of these people, while the last paper includes all observations (N=412), with 298 participants at the final analysis.

Table 1. Overview of the methods used and data in Papers I-IV

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<td>Paper II</td>
<td>2-year follow-up</td>
<td>Qualitative and quantitative analysis, mainly qualitative content analysis</td>
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<td></td>
<td>Questionnaire 2&amp;3</td>
</tr>
<tr>
<td>Paper IV</td>
<td>Long-term follow-up</td>
<td>Quantitative analysis</td>
</tr>
<tr>
<td></td>
<td>412 observations,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>final data</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Questionnaire 3</td>
</tr>
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</table>

Participants completed three questionnaires and produced five blood samples of haemoglobin A1c.

Questionnaire 1: The 12-month survey consisted primarily of background variables, demographic and diabetes-related questions, such as civic status, education, treatment form and duration of disease.

Questionnaire 2: The second survey was distributed 24 months after the baseline. It included an addition of some standard instruments (Eriksson, B.
et al., 1993; Sullivan, M. et al., 1995; Williams, G. et al., 1998; Zigmond, A. et al., 1983) and a number of open-ended questions about patients’ perception of diabetes management. Details can be seen in Table 2.

Questionnaire 3: Administrated at the long-term follow-up measurement, this questionnaire was a combination of open-ended and closed single and multiple questions, such as background questions (age, weight, civic status, smoking and education), diabetes-related questions (treatment, disease duration, complications, anxiety about diabetes, visits to health providers and frequency of self-monitoring of blood glucose) and questions concerning the received social support from a partner. Open-ended questions inquired about informants’ perception of their role and goal in diabetes treatment and need of support, and additional questions about the benefits of the group education. This long-term follow-up survey was collected in 2005.

The first questionnaire was distributed by the group leader at the last meeting, while the second and third questionnaires were mailed to participants’ homes. For all three questionnaires we sent two mail reminders.

The surveys were processed by the Sphinx software with a code number for each observation. This programme allowed direct conversion to the SPSS statistics software.

Table 2. Items for questionnaire nr. 2, administered at 24 months

<table>
<thead>
<tr>
<th>QUESTIONNAIRE ITEMS</th>
<th>QUESTIONNAIRE ITEMS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background variables</td>
<td></td>
</tr>
<tr>
<td>Demographic</td>
<td>Diabetes-related</td>
</tr>
<tr>
<td></td>
<td>Life-style (smoking, physical activity)</td>
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<tr>
<td></td>
<td></td>
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<tr>
<td>Use of health care services</td>
<td></td>
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<tr>
<td>Standard instruments</td>
<td></td>
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<tr>
<td></td>
<td>Swedish SF-36 Health Survey</td>
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<tr>
<td></td>
<td>Hospital Anxiety and Depression Scale (HADS)</td>
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<tr>
<td></td>
<td>Autonomous Reasons Scale</td>
</tr>
<tr>
<td></td>
<td>Autonomy supporting attitude of group leader</td>
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<tr>
<td></td>
<td>Autonomy supporting attitude of health services</td>
</tr>
<tr>
<td>Social support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Diabetes-related attitude of partner</td>
</tr>
<tr>
<td>Own constructions of perceptual variables</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I can sense the glucose level in my body 1-7</td>
</tr>
<tr>
<td></td>
<td>I can guess the exact level of blood glucose in my body 1-7</td>
</tr>
<tr>
<td></td>
<td>I feel responsible for my diabetes management 1-7</td>
</tr>
<tr>
<td></td>
<td>Gender-specific questions</td>
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<tr>
<td></td>
<td>Sexual dysfunction</td>
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<tr>
<td></td>
<td>Social intimacy</td>
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<tr>
<td></td>
<td>Self-blame</td>
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<tr>
<td></td>
<td>Anything special about diabetes as a man/woman</td>
</tr>
<tr>
<td></td>
<td>Open-ended questions about diabetes management</td>
</tr>
<tr>
<td></td>
<td>What is your role in your diabetes management?</td>
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<tr>
<td></td>
<td>What is your goal with your diabetes management?</td>
</tr>
<tr>
<td></td>
<td>What kind of support do you need for your diabetes management?</td>
</tr>
</tbody>
</table>
Outcome measurements of haemoglobin A<sub>1c</sub>

Metabolic control was measured by HbA<sub>1c</sub>, a specific subtype of haemoglobin to which sugar (glucose) in the blood binds. This subtype, haemoglobin A<sub>1c</sub>, has been shown to be linearly associated with glucose levels in the blood and is therefore regarded to be a reliable method for assessing long-term (6-8 weeks) blood glucose control (Tahara, Y. et al., 1995). Swedish national guidelines state that the HbA<sub>1c</sub>-values, which reflect the mean blood glucose concentration over the preceding 6-8 weeks, should not be higher than 6.5 % for good control in type 2 diabetes (Swedish National Board of Health and Welfare, 1999). The reference range for the healthy population is 3.5-5.3%.

Blood samples were collected at the baseline, at six, at twelve (the time of the last meeting) and at twenty-four months, and a further sample was taken at the long-term follow-up measurement (below indexed as t<sub>0</sub>, t<sub>6</sub>, t<sub>12</sub>, t<sub>24</sub>, and t<sub>long-term</sub>). During the study circle period patients took blood glucose tests at the meeting sessions with the help of the group educators, whereas the last two tests (t<sub>24</sub>, and t<sub>long-term</sub>) and their results were sent by mail to the participants’ homes, because these were taken after the intervention.

The HbA<sub>1c</sub> tests were analysed by the same hospital (in Falun, Sweden) at each measurement, measured by the Mono S method (Jeppsson, J.-O. et al., 2002). The results were then sent to Uppsala University, and were communicated to the group leaders who used them as a topic for discussion in the course of the following meetings.

Methods

The measurement of health and disease biology has traditionally been based on quantitative methodology. However, social and psychological scientists who investigate health and health services also employ qualitative methods, with the purpose of understanding people’s perception and behaviour, life- and illness experiences (Patton, M. Q., 1991). From their perspectives, the focus is on the coping strategies, management of a disease and social reactions to illness, health services and health professionals. Within the medical field, nursing research was the first to employ qualitative methods, and these are now an accepted and respected part of nursing research (Polit, D. F., 1999). Qualitative research approaches have also been acknowledged for usage among physicians and other health specialist.

To gain more comprehensive information about the same data, the combination of different methods is a sufficient research strategy, known as ‘data and methodological triangulation’ in the literature (Corner, J., 1991).
Using both qualitative and quantitative approaches helps us broaden our understanding of how to best treat a chronic illness. Such an illness needs to be studied from a combination of perspectives “in order to quantify the effectiveness of treatment and qualify the illness experiences” (Casebeer Ann L et al., 1997; Malterud, K., 2001). To understand the underlying perceptions, beliefs and emotions which drive peoples’ actions, research must take place in a wider context, by observing a person in his/her social environment, under the given life circumstances. These perceptive factors can be articulated most effectively in a narrative manner in the patients’ own words, rather than expressing them in numbers (Holman, H. R., 1993).

Qualitative and quantitative research methods seem to stand as two entirely separate strategies which may complement each other, but are scarcely used within a single analysis. Our data required both statistical and qualitative analyses. The outcomes were expressed by haemoglobin A1c, which is a continuous variable, and the results from the qualitative analyses were taken in relation to the metabolic outcomes throughout the studies. The disapproval of the synthesis of the two methods derives from the differences in the nature and history of qualitative and quantitative research traditions (Sim, J. et al., 1998). The two have always been thought of as opposite research strategies, and for this reason it is not commonly admitted to use qualitative factors in a context of any type of numerical calculation or association. Because of this dismissive tradition, this type of combination of methods in a single analysis is not or seldom described in the literature. It is a fact, however, that the use of both methods in one context can create, and enlighten the relation between quality and quantity. However, the researcher should be aware of the risks when qualitatively labelled variables are converted to numbers. Nevertheless, this stage is essential, because the influence of numbers must be eliminated.

The qualitative method was used in those studies in this thesis, which were aimed at investigating peoples’ perception of diabetes management. Several open-ended questions were asked and then analysed according to principles of qualitative content analysis. This method seemed to be suitable, because it can be applied to different types of texts, both short and long, from notebooks to interviews or diaries. The answers we received belong to the shorter type, which explains why some stages of the analysis process were modified or eliminated, e.g. the condensation of the text was not possible to achieve. This method has a clear, stepwise and structured procedure for starting out from the raw text and getting to the final categories through finding meaningful units, coding and condensation of the text, and defining themes and subcategories (Graneheim, U. H. et al., 2004).

There are two different ways to process the contents of a text. In manifest content analysis the researcher is faithful to words, phrases and what they stand for, whereas in latent content analysis he/she provides the interpretation of the given answers (Graneheim, U. H. et al., 2004). This
difference is exactly what defines our method. Since we strictly worked with the respondents’ expressions and words without considering any underlying meaning, the right method for doing so was evidently manifest content analysis (Woods, L. et al., 2002).

Procedure of the manifest content analysis

Four open-ended questions were included in the content analysis. These questions were: **What is your role in your diabetes management?** **What is your goal with your diabetes management?** **What kind of support do you need for your diabetes management?** Are there any special occasions when you test your blood sugar level? When? See Table 2.

All of the four questions were analysed separately in Paper I, while in Paper II and III the first three of them were included, these being the most important indicators of the participants’ views on managing their illness.

In Paper I the data were sorted according to the content areas, i.e. role, goal, support needs and occasions of blood glucose testing. The analysis started with a thorough reading of every response. Different colours were used for highlighting the areas corresponding to the research questions. The purpose was to find similarities for coding. After several re-readings of the same coded meanings, initial categories were formulated. Following this, the other two members of the research team investigated the resulting categories independently to see if there was an agreement in the categorization. Finally, a consensus was reached.

In Paper II we kept the main three open-ended questions, and each participant’s answers were pulled together in the order of role, goals and support needs, and were treated as a short text consisting of a few sentences. The aim was to capture a global and more comprehensive view of patients’ understanding and perceived role in diabetes treatment. The texts were analysed according to principles of qualitative content analysis (Graneheim, U. H. et al., 2004; Malterud, K., 1996; Malterud, K., 2001).

Paper III was a continuing categorisation of the predetermined categories from the previous study. In order to find agreement of categorisation we carefully worked our way through the specific expressions of each participant. During the first analysis at 24 months we created strict frames for each category, a framework which was also used for the follow-up in the second content analysis. Those who declared to have an active role in the management of their illness or used expressions, such as having “the major” or “the most important” role, to describe themselves, or expressed responsibility for their disease management and at the same time said that they did not need any support from health care providers (or assigned a consultant role to them), were categorized as Disease Managers. If a person
merely described the daily measures of self-care and expressed a definite need to visit health professionals regularly, the assigned category was that of the Compliant. The Disheartened were clearly distinct from the others because they complained not only about the difficulties of diabetes management, but also about health services.

Other researchers from the team reviewed all data after my initial categorisation and, subsequently, meetings were held to discuss deviant cases and agreements. Interestingly, about 20% of all observations showed a discrepancy at both measurements.

Vulnerability in qualitative research – issues of rigor

The reliability of qualitative research is a relevant issue and it should be secured in these studies, as well. Validity of the analysis can be reinforced in terms of credibility, dependability and transferability, these being the most frequently used concepts in the literature (Graneheim, U. H. et al., 2004; Malterud, K., 1996). Credibility can be underpinned by co-researchers using category validation, and by giving the readers derived citation of the text. The former aid was especially important in this study as texts were short, and in 20% of the cases discussed in Paper II and in 22% in Paper III, there was initial disagreement among the researchers. Other scientists (Appleton, J. V., 1995) ensure the truth value of qualitative data by asking other experts in order to reach an agreement on coding, or even by asking respondents to read through the findings themselves. In our case, the findings were presented for other researchers at regular meetings and seminars at the University.

Achieving reliability in qualitative research is often measured by ‘the degree of consistency’ (Polit, D. F., 1999) or dependability. Dependability was enhanced by the fact that data collection was highly consistent, given that the same questionnaire was used over time. Comprehensive descriptions of the analytic process and the explicit criteria for each category were also provided to increase the dependability of our research. Transferability was addressed by comparing our findings with longitudinal studies and constructing a model (Paper II), which provided practical implications for a broader utilization of the results.

Furthermore, researchers paid attention to avoid ‘elite bias’ (overrepresentation of the well-educated and well-articulated informants in the data) and ‘holistic fallacy’ (researchers’ overestimated confidence in the findings) (Appleton, J. V., 1995) by referring back to the data several times, and keeping an open mind for discovering new categories during the analysis.
The neutrality and objectivity of the researcher during the data collection and the analysis constitute an inevitable part of validity. Being someone who is not a health care provider helped me to remain objective throughout, as did the fact that I had no financial dependency or interest of any kind.

Statistical analyses

The data from the questionnaires were at nominal and ordinal levels. Paired t-tests were used to investigate the differences in HbA1c at the five time points of measurement, and ANOVA for testing the differences in HbA1c between the groups from the content analysis.

In Paper I linear regression was employed to find the influential factors in the outcome measurement of HbA1c. The independent variables were entered one by one into the regression model, and the significant ones were kept throughout the analysis. The model was adjusted to two factors, i.e. the initial haemoglobin values HbA1c and BMI, these being constant during the process.

Furthermore, the Chi²-test was used to examine differences between categorical variables.

The qualitative categories were placed into a statistics database as dummy variables. A dummy variable is created from an ordinal scale variable by choosing one of the alternative categories and comparing it with all of the other scale variables. For example, measuring participants’ anxiety about diabetes on a scale: highly, moderately, little, and not anxious at all (Paper IV). These, treated as dummy variables, become: highly=1 and all of the other options together =0; then moderately=1 and all of the others=0 etc.

All statistical analyses were carried out by SPSS (version 11.5 Chicago, SPSS Inc.).

Ethical considerations

All participants gave their written consent to take part in the studies, and we ensured confidentiality. The Ethics Committee of Uppsala University Medical Faculty gave its approval to the study.

Methodological considerations

Participants

There is one general question regarding the choice of participants: Why them? Do they differ from others in the diabetes population? People in the present study population were self-selected, and these results may not generalise for the whole diabetes population. People who apply to
participate in an investigation are perhaps more apt to learn about their illness and to take action in their daily life than others are.

Data collection and design
Unfortunately, when the intervention started in the late 90s, the participants were not asked what they thought about their role in diabetes treatment, nor were they asked about their health conditions at entering the programme. A questionnaire should be handed out at the start of participation in each study circle.

Later, at the long-term follow-up measurement, again, little was known about what happened to participants during the years they were not monitored, i.e. between the two year measurement and the long-term follow-up. A more detailed survey would be needed at the long-term follow-up with specific inquiries about participants’ life events and the received treatment during the time in between assessments.

Furthermore, the data were based on cross-sectional measurements and maybe for better understanding of the role of different factors in self-management development a longitudinal study design would also be required.

Drop-outs
Drop-outs are never desired in any research project. In our studies they can be divided into three groups, those who died (N=35) or dropped out during the intervention period (N=38 of total 508), those who were lost to follow-up, and those who dropped out during an analysis, i.e. ‘internal drop-outs’. This latter phenomenon occurred when a person did not fully fill in a questionnaire or did not give adequate responses. These non-responders reduced the sample size of the studies, especially in Papers II-IV.

Eight responses (4% of 191) in Paper II and nine in Paper III were inadequate and not suitable for any category, e.g. stating “I don’t understand the question” or only putting a question mark on the paper. These answers were treated as unsuitable, and were excluded from the analysis just like the patients of those who did not answer at all (N=45). In Paper III those patients who did not answer the first questions were significantly older than those who had answered the open-ended questions. It seemed that the elderly people might find it more difficult to articulate their needs and a view of self-management, which was required from the participants. Other methods, such as a personal interview, might be more suitable for learning the views of this group.

The net response rate was 53% in Paper III, and drop-out analyses indicate that it is the oldest participants whom we have lost during the
analyses. In Paper IV 114 patients did not answer the questionnaire. However, out of these people 104 had their haemoglobin A\textsubscript{1c} values measured at 12 months, i.e. at the end of the programme. The statistical comparisons showed that the drop-outs had higher blood glucose levels when they finished the intervention as did the participants.

**Qualitative content analyses**

Losing many observations even during the content analyses could be partially explained by the fact that the minimum requirement was an answer to the first question: ‘What is your role in your diabetes management?’, because this question was believed to reflect most clearly the person’s views on diabetes management.

From the methodological point of view the resulting categories (qualitative data) were formulated into statistical calculations, which is considered to be problematic according to the still existing discussion about the differences between the qualitative and quantitative methodologies. It is not common to put the results gained from qualitative measurements into statistical measurements. Practically, however, there is a way in which categories from a qualitative analysis are accepted to be transformed into statistical calculations. Creating dummy variables of a qualitative variable makes this procedure possible. The categories are numbered in the database at ordinal data level, and after creating dummy variables the numbers are not treated as numbers any longer. However, theoretical arguments were not found in the literature for judging whether the used strategy was correct or not. Nevertheless, consultations with statisticians were performed at every measurement.

It is, at this point, necessary to clarify some expressions used in the papers. When the three open-ended questions were drawn into a short text I still used the expression ‘self-perceived roles’, although it was not only the patients’ role which was explored (Paper II and III), but the patients’ support needs and goals, as well. Furthermore, the words ‘attitude’ and ‘perception’ were sometimes used as synonyms of the word ‘view’ in the descriptions of participants’ views of diabetes management. Such a choice of words is to signal that I had no intention of emphasizing the semantic differences of the above expressions either from a psychological or from a cognitive behavioural aspect.
Results

Paper I - The importance of participants’ self-perceived role in disease management

Earlier results from the randomised control trial showed that the study circle programme had an HbA₁c reducing effect (Sarkadi, A. Rosenqvist, U., 2000). This finding stimulated further analyses, and gave a foundation to the first study in this thesis which could explain factors which had influences in maintaining a desired metabolic outcome.

Linear regression was employed with the dependent variable of the two year value of haemoglobinA₁c (HbA₁c t24). The model, based on a sample of 137 informants, revealed the importance of the social network and patients’ self-perceived role in diabetes treatment, as well as the qualitative context of blood glucose monitoring. These two latter factors were gained from the qualitative analysis of the four open-ended questions. Those resulting categories which showed significances in the regression equation are presented in the table below (Table 3.).

Table 3. Significant open-ended questions in the regression model

<table>
<thead>
<tr>
<th>The open-ended questions</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your role in your diabetes management?</td>
<td>Active</td>
</tr>
<tr>
<td></td>
<td>Compliant</td>
</tr>
<tr>
<td></td>
<td>Daily routine</td>
</tr>
<tr>
<td></td>
<td>Passive</td>
</tr>
<tr>
<td>Are there any special occasions when you test your blood sugar level? When?</td>
<td>In case of bodily warning signals</td>
</tr>
<tr>
<td></td>
<td>Testing routine control of status</td>
</tr>
<tr>
<td></td>
<td>Changed diet or exercise routines</td>
</tr>
<tr>
<td></td>
<td>Never test</td>
</tr>
</tbody>
</table>
The metabolic control improved in people who described themselves as having an ‘active’ role in the treatment, as compared to the results of those taking a ‘passive’, ‘compliant’ or ‘daily routine’ role.

Not surprisingly, the treatment form of diabetes also had an impact on the outcomes. Those who were only diet treated had better levels of HbA\(_1c\) than those having tablet or insulin dependent diabetes.

Additionally, the occasion at which the blood glucose monitoring occurred and the partners’ attitude towards diabetes also seemed to be determining factors. Testing blood glucose levels for different purposes, e.g. for routine control of status, in case of bodily warning signals or at changes in diet or exercise, seemed to be better than not testing blood glucose levels at all. It seems reasonable to assume that testing blood glucose provides feedback to patients on how their levels have shifted in relation to the changed routines. This knowledge helps patients take the necessary steps in adjusting their medication or exercise to their current state of health.

The participants’ social support from their partners was measured using 13 items. The questions addressed the spouses’ general interest, practical support and nagging about, or dislike a diabetes-related lifestyle. The possible options on a Likert’s-scale were never, sometimes and always. The only significant item was that one’s partner had changed his or her dietary habits in order to accommodate to those of the respondent’s. Thus, reporting that a partner either never or always adapted his or her dietary habits to those of the respondent meant better results in terms of HbA\(_1c\) at t24 than when the partner was reported to do so sometimes.

Figure 2 below illustrates the significant decrease in HbA\(_1c\) levels between the values of baseline and 6 months (0.33%, p<0.01), and baseline and 24 months (0.15; p<0.05).

The results of this study show that the patients’ perceptions of the positive meaning given to diabetes management and having additional social resources were needed for managing the disease successfully, and the importance of these might even exceed that of the medical factors. This group of patients maintained good metabolic control on the long run (two years) in contrast to other intervention studies, in which most participants achieve a short term glycaemic success lasting from a few months up to one year (Brown, S., 1992). The metabolic success has clinical significance, because even a slight decrease of HbA\(_1c\) reduces the risk of later complications (Reichard, P. et al., 1993).
This study is a further investigation of patients’ self-perceived place in diabetes management. Three of the open-ended questions described in Paper I were: What is your role in your diabetes management? What is your goal with your diabetes management? What kind of support do you need for your diabetes management? The answers of 191 individuals were drawn together and analysed as a short text.

The emerging categories, the so called self-management profiles were: the Disease Managers (N=105), Compliant (N=59) and Disheartened (N=19). The most obvious differences between the categories were participants’ support needs and views of their role in diabetes management. Fewer differences were found in participants’ descriptions of their treatment goals: most of them wanted to achieve and/or maintain a good blood glucose level.
and to live as normally as possible. However, there was a difference in how these goals were described: as a means to avoid threatening complications or to achieve health and well-being.

The quotations below show answers to the three open-ended questions with slashes separating: role / goal / support need.

The **Disease Managers** were 66 females and 39 men with an average age of 63 years, and with a significantly lower average weight than in the other groups, BMI= 27.6. They believed that they had a primary responsibility for their disease and declared that they had an active role in diabetes management.

“I take care of myself / I try to eat as correctly as possible, to continue exercising regularly so that my blood sugar remains on a good level / So far I have been able to manage on my own”

“I have been active in trying to obtain knowledge in different ways: I am a board member of a diabetes association, Internet, literature / I want to feel good and try to manage with tablets [not insulin] as long as possible / I have good support from the doctor and the diabetes nurse. I could imagine taking the study circle programme again”

The **Compliant** could also be called “good patients”, trying to apply all recommendations and knowledge from health care providers to themselves. These people expressed a strong need for regular visits to clinics or diabetes nurses.

A total of 28 men and 31 women were identified with the compliant role. The average age was 64 years, and these people had the longest disease duration of all with an average of 7.5 years, and a BMI value of 28.8.

Again, the quotations below represent answers to the three open-ended questions with slashes separating: role / goal / support need.

“That of the patient’s / To keep [test] results in order / Blood samples and the possibility to see a doctor and nurse”

“To try to eat and exercise as one should / That it doesn’t get worse. It’s good if someone helps out with my diet and exercise. / A good doctor with whom you can discuss everything and who can be summoned for controls”.

Six men and thirteen women belonged to the **Disheartened** group. This is the youngest group with the mean age of 58 years, but with the most overweight participants, BMI=31.8.

Several of the Disheartened stated that they had a “passive” role in managing diabetes. They described poor control over their diabetes and health in
general, and expressed more frustration with fluctuating blood glucose levels as compared to the two previous categories.

“I think I control my food and exercise, but my body still does not obey me. Despite all my efforts, sometimes I have too high values. / A functioning body, brain and heart to get a good HbA1c. / To be taken seriously. The diabetes nurse is good, the doctor is not.”

“Passive role / To keep it at an acceptable level / Sometimes a diabetes nurse, sometimes a dietician, sometimes a doctor.”

“I would like to have a new doctor. The one I have now is not good. The diabetes nurse is good and she listens to me, but the doctor does not. She only sees the diabetes, not me. / To lose weight and to feel as good as possible. Weight loss is the most important thing. / I need help with losing weight, but in my own pace. The past six months have been hard for me, and I want the nursing staff to consider this. My family is very understanding.”

Differences in metabolic control

When the self-management characteristics were compared with the HbA1c values, the differences became visible.

There were no statistically significant differences in the initial HbA1c _t0_ values between the groups. After six months in the study circle, the Disease Managers and the Compliant decreased their HbA1c significantly (p=0.000 and p=0.028, respectively), whereas the Disheartened did not. However, only the Disease Managers could maintain a prolonged reduction with significant differences in their HbA1c between the _t0_ and _t12_ (p=0.001), as well as between the _t0_ and _t24_ measurements (p=0.001). Figure 3

Persons with different self-management preferences showed differences in their demographic data, as well. Some statistical differences appeared in respondents’ age, BMI, duration of diabetes and the treatment form.

The informants who belonged to the Disheartened category were younger than the others (p=0.046). The BMI showed differences with the highest mean value of 31.8 in the Disheartened group (p=0.003). Surprisingly, the Disease Managers and the Disheartened had had diabetes for no longer than 5 years (p=0.008), which was a shorter duration of diabetes than in the case of the Compliant group, who had had it for 7.5 years.

Furthermore, most of the diet-treated members belonged to the group of the Disease Managers (p=0.030), which might be explained by the shorter disease duration.
Figure 3. Self-management profiles and the mean HbA1c-values. P-values indicate statistically significant reduction within groups compared to baseline.

To sum up this qualitative investigation, the main finding is the strong correlation between the way people think about their own role in diabetes treatment and how they achieve metabolic success. Autonomous and responsible roles lead to the best possible result of outcomes in terms of HbA1c. A compliant view is also related to good glycaemic control, but the individuals’ further improvement in their autonomy in self-management may be desirable. The occurrence of Disheartened persons highlights the need for differential treatment in the case of patients with high BMI and low motivation, and actual psychological problems.
We continued working on the above mentioned three open-ended questions inquiring about participants’ self-perceived role, goal and need of support in diabetes treatment, as well as the three established categories (Vég, A. et al., 2006). The first measurement of participants’ perception was conducted at the two-year follow-up of the study circle programme (Paper II), whereas the second measurement is the long-term follow-up presented here. The same individuals from the first analysis were asked to participate in this second measurement, as well. Participants’ clinical data can be seen in Table 4.

The aim was to compare if and how patients’ views shift between the two points of measurement. For this reason, those participants who provided adequate answers to both surveys, were involved in this qualitative analysis. A total of 110 persons matched this criterion.

Our observations showed that people tend to view their role in diabetes management differently over time. (Figure 4) Nearly half of the participants from each category changed their view between the two points of measurement. Numerous directions and variations of shifts within the three kinds of views were noted. The phenomenon of achieving an active role in self-management, as the Disease Managers had, and then changing this attitude and falling into the categories of the Compliant or Disheartened was observed within a couple of years. Similar variations were possible in all of the groups.

Interestingly, no one from among the Disheartened was identified as Compliant at the long-term measurement. The Disheartened seemed to alternate in their self-perceived role in diabetes management to the extremes: they felt that their disease management either works well, or it does not work at all.

The free variation in patients’ perceptions of their diabetes management corresponds with our comprehensive model of self-management development demonstrated in the discussion (p 49). The assumption of a free circulation and repetition of different stages in the learning process of becoming an expert in diabetes self-management seems to be reasonable.
Table 4. Participants’ age, BMI, and HbA1c values (Mean, ±SD) according to their profiles in self-management at long-term follow-up

<table>
<thead>
<tr>
<th>Time after baseline (months)</th>
<th>Disease Managers</th>
<th>Compliant</th>
<th>Disheartened</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=78</td>
<td>N=42</td>
<td>N=19</td>
<td></td>
</tr>
<tr>
<td>HbA1c 0</td>
<td>6.1±1.1</td>
<td>6.3±1.3</td>
<td>6.4±1.3</td>
</tr>
<tr>
<td>HbA1c 6</td>
<td>5.7±1.0</td>
<td>6.0±1.5</td>
<td>6.4±1.2</td>
</tr>
<tr>
<td>HbA1c 12</td>
<td>5.8±1.0</td>
<td>6.1±1.3</td>
<td>6.4±1.0</td>
</tr>
<tr>
<td>HbA1c 24</td>
<td>5.9±0.9</td>
<td>5.9±1.2</td>
<td>6.8±1.4</td>
</tr>
<tr>
<td>HbA1c *</td>
<td>6.2±1.2</td>
<td>6.0±0.9</td>
<td>6.9±1.5</td>
</tr>
<tr>
<td>BMI *</td>
<td>27.6±4.8</td>
<td>28.1±4.3</td>
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</tr>
<tr>
<td>Age *</td>
<td>67</td>
<td>70</td>
<td>70</td>
</tr>
<tr>
<td>Treatment *</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet</td>
<td>5</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>Tablet</td>
<td>33</td>
<td>18</td>
<td>8</td>
</tr>
<tr>
<td>Insulin</td>
<td>12</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Insulin + tablet</td>
<td>27</td>
<td>12</td>
<td>6</td>
</tr>
</tbody>
</table>

* Long-term follow-up, i.e. 3 to 7 years after baseline
Confounding factors

Why, we could ask, do people change their view of their role in disease management?

We found, that weight and age were explanatory factors of the changes of participant’s views of diabetes management. The elderly of the Disease Managers had a tendency of losing the positive view concerning their role in diabetes management, which could be explained by the progression and worsening of diabetes. Accelerated aging in diabetes has been related to cognitive and emotional decline, which in turn could counteract optimal glucose-regulation (Messier, C., 2005).
Those who were younger, such as the Disheartened with an average age of 58 years, did, on the contrary, change their views of diabetes positively compared with the older Disheartened persons.

Obesity was another explanatory factor for change, observed among those of the Compliant who became Disheartened (BMI=37). This change seemed to occur if a person had a higher BMI, whereas the Compliant who were lighter more often became Disease Managers (BMI=27.4). This is quite in accordance with the literature, where higher BMI is often linked to poor metabolic control and other cardiovascular diseases (Ridderstrale, M. et al., 2006), as well as to depression (Sacco, W. P. et al., 2005).

**Variation in views and metabolic control**

On the group level similar results were found in participants’ views of diabetes management and metabolic control as were at the two year measurement.

In sum, the results of Papers II-III would suggest that the characteristics of a Disease Manager was always related to excellent glucose control, the Compliant succeeded in keeping good control, whereas the Disheartened had poor metabolic control during the study periods.

How does the changing of views influence metabolic control? The sample size may have been too small to draw conclusion, e.g. the low number of persons who changed from being Compliant to Disheartened (N=3), from Disease Manager to Disheartened (N=5) and from Disheartened to Disease Manager (N=8). Interestingly, the raw HbA1c values did not yield an improvement in blood glucose regulation in the cases of eight Disheartened persons who shifted their views to Disease Manager. An assumption, without statistical confirmation, may be that one’s (in)ability to control blood glucose levels subsists even when the perception of one’s own role in the treatment has changed. Another possibility is that the changes in perception and understanding are not strictly followed by a positive shift in metabolic control.
Paper IV – Metabolic control in the long run

The last study included in this thesis describes the metabolic outcomes of the study population in means of HbA1c years after finishing the intervention, and provides a detailed description of the procedure of the intervention. The key point of this study is that it is a cross-sectional measurement, which was carried out regardless of the number of years that had passed after entering the programme. Thus, the range of the long-term follow-up was from 3 to 7 years. A total of 412 persons were re-examined for up to 7 years after the beginning of the intervention. Of the 412 informants 298 (72%) participated in this investigation, and 114 (28%) individuals did not answer the questionnaire. Out of 298 individuals 107 were men and 191 women, having a mean BMI value of 28.3.

The metabolic outcomes as measured by HbA1c were described on the study population level and separately for each time point of the long-term follow-up, which can be seen in the table below (Table 5).

A decrease in HbA1c was observed during the intervention year: 0.31%, after six months (p=0.000) and 0.19% after 12 months, (p=0.000). However, after the completed intervention at 12 months, the participants’ haemoglobin A1c values increased. The difference between the HbA1c t12 and the HbA1c long-term was statistically significant (p=0.001), which means a 0.2% increase.

In contrast, a tendency of HbA1c reduction up to two years, i.e. the discrepancy between the HbA1c t0 and the HbA1c t24 values (0.09%), was observed as at earlier measurements.

One factor besides the metabolic perspective of the study that was kept in mind throughout was the psychological viewpoint. The question of anxiety about diabetes treatment highlighted differences in relation to metabolic outcomes. Those who felt a moderate anxiety about diabetes had a higher HbA1c level compared to others p=0.013 (mean HbA1clong-term 6.5%, and 6.1% respectively), whereas a little anxiety had a positive effect on blood glucose control, p=0.011.

The impact of psychological and emotional factors on metabolic control shows inconsistency in the literature. Lane et al. reported inverse effects on HbA1c, i.e. a higher score in six personality domains resulted in worse glycaemic control (Lane, J. et al., 2000), whereas others observed a lower level of HbA1c as a consequence of negative emotions (Wiebe, D. J. et al., 1994). Similarly to the latter finding, our results also underlined the negative effect of more expressed anxiety about diabetes and its complications related to blood glucose levels.

Moreover, it had been examined whether the blood glucose values of the drop-outs was different from the values of those who participated in the study. Of the 114 drop-outs from this study 104 had a haemoglobin A1c
value taken at the end of the intervention (t_{12}). Statistically significant differences were found between the two groups, the drop-outs having an HbA_{1c} t_{12} level at 6.3%, and the non drop-outs at 6.0% (p=0.026).

To summarise the findings, this is a cross-sectional study reporting on the long-term follow-up of HbA_{1c} modification of a study group population. The question arises whether an active learning of diabetes management helps adults with a chronic condition to utilise the skills they had learnt during the intervention several years later. We do not have information on the medical and educational circumstances of the participants between the two year and the long-term follow-up measurements which could confound the effects of the intervention. However, in comparison to the findings described by the United Kingdom Prospective Diabetes Study group, where the increase of HbA_{1c} in a large population was described in intensively treated patients as well (United Kingdom Prospective Diabetes Study Group, 1998), the stability in haemoglobin A_{1c} over several years in this study is a clinically significant result.

<table>
<thead>
<tr>
<th>F-up</th>
<th>Age</th>
<th>HbA_{1c}</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>t_0 t_6 t_{12} t_{24} t_{long-term}</td>
</tr>
<tr>
<td>3-yr</td>
<td>Mean</td>
<td>67</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>64</td>
</tr>
<tr>
<td></td>
<td>St. D.</td>
<td>1.27</td>
</tr>
<tr>
<td>4-yr</td>
<td>Mean</td>
<td>68</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>71</td>
</tr>
<tr>
<td></td>
<td>St. D.</td>
<td>1.15</td>
</tr>
<tr>
<td>5-yr</td>
<td>Mean</td>
<td>68</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>80</td>
</tr>
<tr>
<td></td>
<td>St. D.</td>
<td>1.20</td>
</tr>
<tr>
<td>6-yr</td>
<td>Mean</td>
<td>69</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>St. D.</td>
<td>1.37</td>
</tr>
<tr>
<td>7-yr</td>
<td>Mean</td>
<td>70</td>
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<tr>
<td></td>
<td>N</td>
<td>61</td>
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<tr>
<td></td>
<td>St. D.</td>
<td>1.32</td>
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<tr>
<td>Total</td>
<td>Mean</td>
<td>68</td>
</tr>
<tr>
<td></td>
<td>N*</td>
<td>296</td>
</tr>
</tbody>
</table>

* 2 persons had 8 year follow-up yielding a total study population of N=298
Summary of the results

The study circle programme, led by specially trained pharmacists, ran for seven years between 1997 and 2004. Altogether 508 participants from 60 study circles completed the whole group education programme. A total of 38 (7.5%) participants left the study and as far as we know, 35 (6.9%) died. Pharmacies in 18 cities in Sweden started one or more study circles, and these have worked successfully in teaching self-management principles and skills to people with type 2 diabetes. This type of education also seems to be effective in showing people how to live well with a chronic condition, by enhancing their understanding of their disease and its management. Consequently, participants succeeded in decreasing their blood glucose levels and keeping them low over a long period of time. Three describing categories of respondents’ self-perceived role in diabetes management were formulated from a combination of qualitative and quantitative analyses. The resulting self-management profiles of participants were strongly related to metabolic outcomes. Patients taking care of diabetes most effectively were called Disease Managers; those following the health professionals’ orders were identified with the role of Compliant, whereas the Disheartened had difficulties in achieving good metabolic control.

This study also investigated the changes in perceptions recorded over several years. The perceptions of diabetes management were only stable in the case of approximately half of the participants, thus providing evidence for a dynamic model of learning self-management in diabetes. The results underline the fact that knowledge by itself cannot improve outcomes; the knowledge needs to be understood and integrated in daily life, and enhanced by experiences and reflective learning.

Moreover, our experiences from this group education programme show that teaching people with a chronic condition does not necessarily require a direct connection with the health care system.
Discussion

The results from this thesis can be summarised as follows:

- patients’ self-perceived role in diabetes management can be systematically examined and described, and it has a bearing on haemoglobin A1c values
- prolonged good metabolic control was seen after the reflective and experience-based learning in the study population

Let us start by discussing the possible impact of the educational programme on participants’ metabolic control. Although an indirect purpose of the educational intervention was to improve participants’ understanding of diabetes and its management, measuring understanding in depth is a complex endeavour, and we do not claim to have done it in a fully comprehensive manner. However, by asking participants to describe their perceptions of several aspects of self-management, we have gained a certain insight into their experiences.

Becoming a Disease Manager – an educational effect?

In the present study, Disease Managers were characterized as persons with a feeling of being in control of their own blood glucose and being conscious of how to influence it and keep it low. These patients took their health primarily into their own hands, and had an independent role in self-management. In this manner, our conception of the Disease Managers was in concordance with the British description of ‘expert patients’. The Expert Patients Programme is a self-management programme for people with chronic illnesses, developed in the late 1990s in Great Britain. The idea of the initiative was to reinforce patients’ confidence and motivation for taking responsibility for disease management and attaining greater control over their lives (NHS 2001).

Several questions arise in regard to the resulting self-management profiles: Has this patient education programme made people become Disease Managers, or did these self-management profiles exist before the
programme? If it is the latter case, had the programme added any skills or strategies that enhanced the metabolic control of Disease Managers? And finally, do these profiles reliably predict metabolic control?

Unfortunately, this study did not explore the individual skills or cognitive efficiency for managing a chronic condition at entering the intervention. However, some facts may be of assistance in answering the above questions.

The existence of the three self-management profiles prior to the programme is supported by findings from the randomised controlled trial (Sarkadi, A. Rosenqvist, U., 2004). The control persons (N=38) also received the 24-month questionnaire and blood tests. Of 27 completed questionnaires 19 informants had analysable answers to the earlier described three open-ended questions. It was, indeed, possible to identify the three self-management profiles among the participants from the control group: 6 persons were Disease Managers, 7 were Compliant and 6 were Disheartened. Interestingly, the control Disease Managers had higher HbA1c t24- values than the Disease Managers in the intervention groups. This would mean that these Disease Managers did not have the appropriate skills for successful self-management before they started a study group, but did display an independent/autonomous perception of their own role in relation to diabetes treatment. However, no differences occurred in the Compliant and Disheartened groups at similar comparisons.

If we accept the assumption that distinctly different perceptions of self-management exist prior to the intervention, it is interesting to know whether this has any bearing on baseline HbA1c. From the initial blood glucose values it can be seen that the Disease Managers were no more advanced in terms of metabolic control at the baseline than people from the Compliant or Disheartened groups. (See the Figure 3 on p 36) As there were no statistical differences between the three profiles of participants, the hypothesis that participants with a certain self-management profile were more skilled than others in controlling their diabetes at entering the intervention was not supported. However, we obviously do not know which category of self-management participants belonged to at baseline.

People with diabetes may, thus, view themselves as Disease Managers without showing any change in their metabolic control. The question then is: What makes a Disease Manager with acceptable metabolic control become one with excellent control? It seems likely that participants learned disease-specific skills in the study circle because the Disease Managers from the intervention group had reduced their HbA1c and succeeded in keeping it low during the two year or longer observation period.

Another interesting observation was made in connection with those Disheartened persons who, in the long-term follow-up, expressed a view of being Disease Managers without improving their metabolic outcomes. Consequently, the perception of being a Disease Manager could be viewed
as predictive of, but not in all cases sufficient for successful metabolic control.

What, then, did this group education specifically do to help participants become better at regulating their blood glucose?

The intervention – Focus on reflection and understanding

The central concepts of the programme can be summarised in three main points: reflection, understanding and experiences. Participants’ problems and the immediate current interest related to diabetes treatment were discussed both with others with the same diagnosis and with experts in a group, providing ample opportunities for reflection. In earlier studies it has been shown that the use of reflective techniques in the learning process is suitable in the treatment of chronic illnesses (Holmström, I. et al., 2001; Saleh Stattin, N., 2001). Focusing on participants’ understanding of diabetes was an important didactic strategy because patients usually had information or knowledge about diabetes treatment, but they did not necessarily understand how to manage the disease and integrate the new knowledge into their daily routines (Holmstrom, I. Rosenqvist, U., 2005). The main point of the experience was to discover new situations, and learn more by ‘trial and error’ or experiments, thus working towards a better understanding of diabetes management.

The programme integrated both reflective learning and practice: books and games promoted learning and understanding the meaning of diabetes treatment, while practicing blood glucose monitoring and trying different kind of foods seemed to help individuals to use their knowledge in everyday activities. Purchasing and preparing food together raised awareness and granted practical skills and, at the same time, designated the diabetes lifestyle as the norm rather than something confined or over-complicated.

The study circle programme differs from other patient education models from another important aspect, as well: this intervention left the frame of traditional health care by employing pharmacists as group leaders and having the meetings at pharmacies or community facilities rather than primary care surgeries or hospitals (Sarkadi, A., 2001).

The role of the educator

To teach and enable people to become great self- and disease managers poses a significant pedagogical challenge for health care providers. However, in my view, the pedagogical preparation of health care professionals for encountering chronically ill people is not given enough attention in the organisation of health care.
In conventional care, a dependent relation between the patient and the health provider is still common, i.e. the competence and responsibility mainly lies in the hands of the educator who, in turn, teaches the patient what to do. According to a more modern trend, however, patient education is broadened by the caregivers’ openness for interchanging experiences, which means allowing the patient to manage the encounter (Friberg, F. et al., 2005). However, to become an educator who facilitates rather than instructs, who acknowledges the different phases in developing self-management and acts accordingly - sometimes sacrificing medical priorities - cannot be done overnight. Reflection on the part of the educator is needed.

Holmström et al. showed that health care providers can, indeed, be taught to place the focus on the patient’s needs more in the encounter. The authors carried out an intervention based on videotaped consultations and guided reflections on what had happened in the patient-physician encounter. Differences in attitudes and observable alterations of the physician’s consultation style back at work were described (Holmström, I. Rosenqvist, U., 2001). Changes of the physicians’ understanding of what care in diabetes entails helped them become more patient-centred in their clinical practise (Holmstrom, I. et al., 2000).

The group educators in the present intervention improved their pedagogical competence by participating in a three-day long training course before initiating a study circle. They shared the experiences of diabetes lifestyle by shopping and preparing appropriate foods, learning to monitor their blood glucose levels, and testing the effects of exercise or sweets on their blood sugar levels. The same pedagogical principles were employed throughout the training course as the leaders were expected to practice: encouraging experiments and facilitating the group to answer its own questions.

The special course given to physicians as well as the training programme the group leaders participated in are examples of an effective way to advance patient-centred attitudes. If health care workers are to become as good educators as they are clinicians, systematic programmes to improve pedagogical competence have to be implemented.

Learning self-management in diabetes

To illustrate the learning of self-management in diabetes a single comprehensive model (Figure 5) had been summarised of the existing research in the field and was then altered based on our experiences. The intention was to compare models based on longitudinal experiences of learning self-management in diabetes with the self-management profiles identified in this cross-sectional study. The studies on which the model is

In contrast to other studies, we emphasize that there is not necessarily a linear relationship between the stages of learning self-management, defined in this model: passive compliance, compliance, basic routine, rebellion, transitory dependence, active control and expert patient. There is rather a possibility of free circulation between these stages.

The terminology, from ‘novice to expert’, was used by Benner to illustrate competence development of care providers (Benner, P., 1984). Being a novice in diabetes is seen as a starting point directly after the diagnoses, in my illustration in this model. The step of passive compliance, as I see it, is a status when no autonomy has been achieved in disease management and learning is characterized by receiving information. This stage is most often considered to appear after diagnosing the disease or after a relapse. In contrast, the stage of compliance stands for having routines that strictly follow the directions from care givers to manage diabetes. A similar phase, termed basic routine in Price’s model, was described as an important learning stage. Price divided the learning process into two main phases, where phase two stretched from basic routine through experience to a more complex level of self-management. This higher stage of self-management, in agreement with other findings, could be identified as the state of active control in this model. Finally, becoming an expert patient entails a level of competence where the individual is able to change a well-functioning routine and adapt it to new situations, such as having fever or being on vacation.

The state of being rebellious or in transitory dependence may be caused by a difficult temporary life situation or other obstacles in the way of managing the disease as it would be desired. Experiences of being in such phases are important building blocks of the road leading to expert diabetes management. While one would expect these relapses to be counterproductive, it seems, in fact, that people receive a great deal of experience and learn more from relapsing than when they experience no setbacks at all (Basler, H. D., 1995).

The three studies referred to were based on retrospective interviews of expert patients. In contrast to Price’s step-by-step model with some overlapping conditions in between, in Ellison & Rayman’s study the process of learning diabetes self-management was described in three phases: “Management as rules”, “Management as work”, and “Management as living”. The women participating in the above study moved forward and backward between the phases: sometimes self-management worked satisfactorily, whereas at other times these patients had a feeling of going back to an earlier stage. The third model referred to described four distinct phases on an evolutionary trajectory, and showed no evidence of all
individuals necessarily going through every stage. However, all participants experienced the role of passive compliance in the beginning of the treatment.

In addition, there are also a number of external factors that affect the developmental process of learning to deal with diabetes in everyday life. Thus, achieving successful control strongly depends on the individuals’ personal resources and their social background, including the prospect of getting sufficient educational, emotional, practical and professional support.

How, then, do the three profiles of self-management from the present findings fit into the developmental model of learning self-management? The place of the Compliant and Disease Manager categories is given. It seems that the Compliant person exists as a recognisable “link” in the health care system, because of the compliance orientation in physicians’ and nurses’ practices. The position of the Disease Managers is determined as a “final destination” or the outcome of this developmental model of self-management. The Disheartened group, however, could correspond to
different stages. An individual who is “diagnosed” as Disheartened right now could either be experiencing the stage of ‘rebellion’ or be in a ‘transitory dependent’ role.

The model and the stages, however, are dynamic because people’s views change over time, as we found in the third study. We claim, based on our results, that an individual may relapse to a previous level of self-management at any achieved level. We did, in fact, see elderly Disease Managers who had changed their perceptions and were categorised as Disheartened at the second measurement. It is conceivable that Disease Managers could get stuck in a role of rebellion or transitory dependency due to a current obstacle in their disease management. On the contrary, we could see a positive shift happening when the younger of the Disheartened patients expressed having a Disease Manager’s role at the follow-up.

Clinical applications, the benefit of the studies

The main benefit of the studies is the possibility to plan the secondary preventive efforts of chronic diseases more effectively and thereby improve health care services. The finding of the three self-management profiles of people with type 2 diabetes makes the establishment of a ‘self-management diagnosis’ in the clinical practice possible. This can be achieved at any given time by asking patients to answer the three questions described earlier. Therefore, the challenge for the health care system is to become more flexible and capable of offering different types of services to patients with different needs.

Thus, two main questions arise regarding the practical performance:

1) How can we best support individuals with chronic conditions based on their self-management profiles?
2) How can we integrate these patients into the health care system?

Ad 1 It seems evident from the model that people with a chronic illness need different kinds of support at each level of their self-management evolution, which, in turn means different tasks for health professionals in their encounter with patients (Table 6). The Disease Managers need to be respected in their autonomy, while retaining all rights for support in further developing their skills and knowledge, as well as in case of a relapse to another level of self-management capacity. The Compliant might, instead, have to be encouraged to risk leaving a strict schedule and experiment a little in order to move ahead in the cycle of self-management development. The Disheartened, in turn, might need a hindrance analysis and better skills to be
able to leave a negative/relapse period more rapidly. In the case of the Disheartened, enhancing a feeling of responsibility for their own health is also a task for health care professionals.

Table 6: Practical implication for treatment of patients with different needs in disease management

<table>
<thead>
<tr>
<th>Diagnostic questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your role in your disease management?</td>
</tr>
<tr>
<td>What is your goal with your disease management?</td>
</tr>
<tr>
<td>What kind of support do you need for your disease management?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Self-management “diagnosis”</th>
<th>Support/suggestion for self-management programmes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease Manager</td>
<td>Respect for their autonomy, Further developing of skills</td>
</tr>
<tr>
<td>Compliant</td>
<td>Facilitating and motivating to new challenges, and experimentations, Enhancing autonomy</td>
</tr>
<tr>
<td>Disheartened</td>
<td>Increasing awareness/knowledge and responsibility, hindrance analysis</td>
</tr>
</tbody>
</table>

Ad 2 The Compliant role seems least controversial, fitting well into the health care system. The Disease Managers, although they are expected to be a part of today’s health care system, are not always provided an opportunity to utilize their competence. As pointed out earlier (Role of the Educator) it is a professional challenge to guide expert patients and requires knowledge, respect and reflection on the part of the educator.

We should also remember that at the same time a group of patients, the Disheartened in this study, seem to lose control from time to time and are often unable to achieve and keep an acceptable control over their disease. This group of patients needs more support for solving the current difficulties in their disease management, which can be obesity, psychosocial problems or other hindrances in living with the disease.
Improving diabetes management in the current health care system

Despite the large quantity of research and clinical trials performed there is still little knowledge as to what the most efficient practice would be. In the table below three main areas are chosen, which I believe are the most essential components of diabetes management. These areas are: prevention of diabetes-related complications, patient education and patients’ involvement in the decision-making process. The two latter areas are also considered to be relevant for the care of other chronic diseases. The development of these factors will be presented with recommendations for future diabetes management from the perspectives of the health care system and the patient, as well.

Prevention of diabetes-related complications. Most of the persons with type 2 diabetes have high blood glucose levels (HbA\textsubscript{1c} \geq 6.5 \%) and cannot manage to attain an optimal metabolic control (WHO and IDF (Europe), 1990). The problem with high blood glucose levels during a longer period is that they may cause renal failure, eye injuries and vascular disorder (United Kingdom Prospective Diabetes Study Group, 1998) which, in turn, may lead to a considerably shorter life expectancy. We know that improved blood glucose control could reduce the risk of micro- and macrovascular complications (Bradley, C., 1995; Reichard, P. \textit{et al.}, 1993). A further problem is the high percentage of undiagnosed patients, which has lead to emphasizing the need for screening for type 2 diabetes, as well as the necessity health education in preventive health work.

Patient education. The pedagogical orientation in patient education has shifted from an information-based approach to problem-oriented and active learning in order to improve patients’ understanding (Rosenqvist, U. \textit{et al.}, 1995). In the future this area should continue to focus more on the individuals’ role perception and the patients’ learning needs and at the same time expand the frame of patient education outside of the health care organisation.

Patients’ involvement in the decision-making process. The high-quality self-care and management of a chronic condition means not only attaining a satisfactory metabolic control, but also participating more in the treatment. It requires a different kind of communication and encounter in health care than emergency care does (Szasz, T. S. \textit{et al.}, 1956). Patient empowerment has become a cornerstone of improving the patient-doctor relationship in chronic diseases, and consequently, patient-centeredness has evolved as a concept (Coulter, A. \textit{et al.}, 2002; Little, P. \textit{et al.}, 2001). A partnership between the health care seeker and the health care provider may be achieved through patient-oriented care where the patients’ autonomy and competence are in focus (Cooper, H. C. \textit{et al.}, 2003; Mead, N. \textit{et al.}, 2002; Mühlhauser, I.
Berger, M., 2000; Williams, G. C. et al., 2002), applying reflective-based consultation in care. This is the point where diabetes treatment calls the health professionals for improvement of their pedagogical competence. Doctors and nurses should have the appropriate pedagogical skills and be ready to take care of different kinds of patients on an equal level. To recognise patients with different needs, the educational tool presented in Table 6 would be applicable. Patients, in turn, should be well educated disease-specifically, and should take the responsibility for their disease management, where this responsibility sometimes entails asking for more help or setting more realistic treatment goals.

In envisioning future health care, I would like to see a system where a health care provider may have a consultant’s role in the treatment of persons with different needs and self-management profiles in chronic diseases. The question is whether the health care system is ready to offer differential care and to receive the new generation of patients, both expert Disease Managers and those who have difficulties, like the group of the Disheartened patients.

Table 7. Tasks for improvement of diabetes care in three main areas

<table>
<thead>
<tr>
<th>Health providers’ role</th>
<th>Individuals’ role</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Avoiding complications</strong></td>
<td><strong>Present</strong></td>
</tr>
<tr>
<td>Past practices</td>
<td>Screen and organised care</td>
</tr>
<tr>
<td>Less emphasis on prevention</td>
<td></td>
</tr>
</tbody>
</table>

| **Patient education** | **Past** | **Future** |
| Information-based | Focus on active learning & patient’s understanding | Focus on self-perception and reflective learning |
| | | Integration of knowledge, Develop own competence |

| **Encounter** | **Past** | **Future** |
| Less patient involvement | Put patient in the centre | Consult role, using pedagogical tools for differential care |
| | | Competent, expert patient who sets own priorities |
Conclusions

The main message of this thesis is that participants’ self-perceived role has a major influence on metabolic outcomes. Assessing self-management profiles both in diabetes and possibly other chronic conditions can help health care providers to tailor their educational efforts accordingly. Furthermore, this experience-based patient education programme, outside the framework of routine diabetes care, has the potential to effectively stabilise metabolic control on the long run.

Following from these statements the big challenges for health care providers are:

- to improve their own pedagogical competence and use techniques, such as reflective and experience-based learning
- to have more discussions about patients’ self-perceived roles in disease management
- to recognise patients with different needs, and
- to become more flexible and adjust the health services to patients’ different needs and characteristics
“We are talking about a basic human competence – the ability to learn on one’s own – that has suddenly become a prerequisite for living in this new world” (Knowles, 1975)

My intention with this epilogue is to once again underline the importance of learning in chronic diseases. Continuing and adapting the above citation to the area of disease management, I would say that patients have the ability to learn and take responsibility for their chronic condition on their own.

It was, thus, with pleasure that I realised that an educational programme for type 2 diabetes, one which became responsible for, promised to highlight ‘individual-centeredness’ which is evident from my point of view. This was a programme with specific focus on individual learning with considerable pedagogic competence in the design. The research group I joined had already proved that the educational programme was, indeed, effective and it was also clear that some individuals fared better than others after having completed a year of the group education. Just as the experiences taken from the education of people with disabilities, which I have referred to in the Introduction, the present results have also shown that the way persons with type 2 diabetes learn disease management differs for each patient. These individual differences in learning will, in turn, require personalised treatment forms and learning plans.

A final and simple message of this thesis is that it is possible to learn disease management. However, as it was shown, not all patients had the ability to become experts in their disease management, but it is possible to be better and improve health outcomes in chronic illnesses. If the common goal is to obtain and maintain optimal metabolic control and have a good quality of life with the disease, communication between doctors, nurses and patients, as well as the process of teaching and learning has to work efficiently and in complete harmony in order to steer the boat in the right direction. Sometimes, however, storms may come, which may shake our vessel, push it towards unfriendly waters or even turn it over. Storms, such as unexpected events in one’s life, a sudden illness or unfavourable conditions may rattle the boat badly. But after the first blizzard we will know how to deal with such situations. With reflective learning and cooperation we can become master seamen, and row, with full control of the helm, to faraway oceans.

Arbete I: Linjär regression användes för att ta reda på vilka faktorer som hade störst betydelse för utfallet d v s blodsockernivån två år efter baslinjen. Individernas uppfattning om sin roll i behandlingen visade sig påverka blodsockernivån. En aktiv och självbestämmande syn och även en följsam attityd till diabetes behandlingen hade en sänkande effekt, medan en passiv syn resulterade i förhöjda blodsockervärden.


Arbete III: Det tredje arbetet var en fortsättning av det andra dvs. samma individer var involverade i studien och samma metod användes i analysprocessen. Vi ville ta reda på hur stabila personernas uppfattning om sin roll i diabetesbehandlingen var flera år efter interventionen och om det fortfarande visade signifikant samband med blodsockernivåerna. Resultaten
bekräftade att det fanns en stark relation mellan patienternas uppfattning/förståelse av diabetesbehandlingen och den långsiktiga metaboliska kontrollen även om personens uppfattningar varierade över tid.

**Arbete IV:** Syftet med detta arbete var att följa upp alla deltagare från studieprogrammet och se hur det gått för dem flera år efter interventionen. Vidare belystes särskilt betydelsen av oron över sjukdomens möjliga senkomplikationer; det kom fram att en liten oro hade positiv effekt för hur man hanterade sin diabetes, medan en högre känsla av oro påverkade deltagarnas blodsockernivåer negativt. Huvudfynden av denna studie var att våra deltagare verkade kunna konstanthålla sin HbA1c över den observerade perioden up till 7 år. Detta kan förklaras av olika faktorer, men en hypotes kan vara att om man någon gång lärt sig att styra sitt blodsocker skulle dessa kunskaper bibehållas och ge effekt lång tid framöver. I denna, avhandlingens sista artikel, beskrevs dessutom den experimentbaserade och deltagarstyrda patientutbildningens nyhetsvärde och styrka.

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References

(CoQoHC, 2001) Committee on Quality of Health Care in America Crossing the Quality Chasm: A New Health System for the 21st Century. Institute of Medicine, Washington DC, America.


Bagust, A., Hopkinson, P.K., Maslove, L. and Currie, C.J. (2002): The projected health care burden of Type 2 diabetes in the UK from 2000 to 2060. Diabetic Medicine, 19, 1-5.


Byström, J. (1983) *Studiecirkeln pedagogik (Pedagogy of the study circle).* Kristianstads Boktryckeri AB, Kristianstad.


Jonsson, A. (1995) "Lära sig att bli den människa man måste bli" ("To learn to be the person one has to be"). Stockholm University, Dept. of Education, Stockholm.


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