Quality of Care in Children and Adolescents with Type 1 Diabetes
- Patients’ and Healthcare Professionals’ Perspectives

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“Just think of how much you can see although the eyes are so small”

Pelle, at 4 years of age
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ABSTRACT

Background: Type 1 diabetes is a chronic disease for which there is currently no cure, and high quality care is essential if acute and long-term complications are to be avoided. Many children and adolescents have inadequate metabolic control with increased risk for complications later in life, and adolescent girls have reported low quality of life. Differences in metabolic control between treatment centres have been found but the reasons for this are unclear. Diabetes is a largely self-managed disease. Patient education is central to successful self-management but little is known about how to make best use of diabetes communities on the Internet and integrate them into a practitioner-driven service.

Aim: The main objective of this thesis was to gain better understanding of how to improve the quality of diabetes care for children and adolescents, aiming to have near-normal blood glucose, to prevent both acute and late complications and to have good quality of life.

Methods: The geographic populations of two paediatric centres (n=400) received validated questionnaires on perceived quality of care and Health-Related Quality of Life (HRQOL). An intervention with a web portal containing diabetes-related information and social networking functions was carried out within the same population. Clinical variables from 18 651 outpatient visits registered in the Swedish paediatric diabetes quality registry, SWEDIABKIDS were analysed. Using data from SWEDIABKIDS, five centres with the lowest mean HbA1c, five with the highest, and five with the largest decrease in centre mean HbA1c between 2003 and 2007 were identified. Team members (n=128) were asked about structure, process, policy, and the messages given to patients about important diabetes issues.

Results: Specific areas that were identified as needing improvement included information about self-care, waiting time at outpatient clinics and for treatment, and access to care. Diabetes seemed to reduce HRQOL. Subjects with better metabolic control and with higher frequency of injections reported slightly higher HRQOL, as did those living with both parents compared to those with separated parents. Only 35% of children and adolescents with diabetes in Sweden had an HbA1c level below the treatment target value. Mean HbA1c showed a correlation with mean insulin dose, diabetes duration, and age. A difference between centres was found, but this could not be explained by differences in insulin dose, diabetes duration, or age. Adolescent girls reported lower HRQOL, as did parents of girls aged < 8 years. Girls also had poorer metabolic control, especially during adolescence.

In teams with the lowest and the most decreased mean HbA1c, members gave a clear message to patients and parents and had a lower HbA1c target value. Members of these teams appeared more engaged, with a more positive attitude and a greater sense of working as a team. Members of teams with the highest mean HbA1c gave a vaguer message, felt they needed clearer guidelines, and had a perception of poor collaboration within the team. High insulin dose, large centre population, and larger teams also seemed to characterize diabetes centres with low mean HbA1c. The most frequently visited pages on the web portal were the social networking pages, such as blogs, stories and discussions, followed by the diabetes team pages. Those who used the portal most actively were younger, had shorter diabetes duration, and lower HbA1c, and were more often girls. The web portal was not found to have any significant beneficial or adverse effects on HRQOL, empowerment or metabolic control.

Conclusions: The quality of diabetes care for children and adolescents in Sweden is not sufficiently good and needs to improve further if complications in later life are to be avoided. Psychosocial support for children and adolescents with diabetes should be appropriate for age and gender. The attitudes of the members in the diabetes care team and the message they give to patients and their parents seem to influence metabolic control in children and adolescents. A clear and consistent message from a unified team appears to have beneficial effects on metabolic control. A web portal that includes comprehensive information about diabetes, and the opportunity to communicate with other people with diabetes and with healthcare professionals may be a useful complement to traditional patient education tools. Members of the diabetes team should encourage its use.
SWEDISH SUMMARY / SAMMANFATTNING PÅ SVENSKA


Syfte: Huvudsyftet med den här avhandlingen var att få bättre förståelse för hur kvaliteten inom vården av barn och ungdomar med diabetes ska kunna förbättras, så att blodsockerkontrollen blir så nära normal som möjligt, så att både akuta och senare komplikationer förebyggs och att livskvaliteten blir god.


Slutsatsar: Kvaliteten inom vården av barn och ungdomar med diabetes är inte tillfredsställande god och behöver förbättras om komplikationer senare i livet ska kunna förebyggas. Det psykosociala stödet behöver anpassas efter ålder och kön. Attityden hos diabetesteamets medlemmar och det budskap de ger till patienterna och deras föräldrar verkar påverka den metabola kontrollen hos barn och ungdomar. Ett klart och samstämmigt budskap från ett enigt team verka ha fördelaktig effekt på den metabola...
ORIGINAL PUBLICATIONS

The present thesis is based on the following studies which will be referred to in the text by their Roman numerals:


IV. Hanberger L, Samuelsson U, Berterö C, Ludvigsson J: The influence of process, structure and policy on haemoglobin A1c levels in treatment of children and adolescents with type 1 diabetes. (Submitted)

V. Hanberger L, Ludvigsson J, Nordfeldt S: Use of a web 2.0 portal to improve education and communication in young diabetes patients with families – a case study. (Manuscript)
# ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>BMI</td>
<td>Body Mass Index</td>
</tr>
<tr>
<td>CSII</td>
<td>Continuous Subcutaneous Insulin Infusion</td>
</tr>
<tr>
<td>DCCT</td>
<td>The Diabetes Control and Complication Trial Research Group</td>
</tr>
<tr>
<td>HbA1c</td>
<td>Hemoglobin A1c</td>
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<tr>
<td>HRQOL</td>
<td>Health-Related Quality of Life</td>
</tr>
<tr>
<td>IDF</td>
<td>International Diabetes Federation</td>
</tr>
<tr>
<td>IFCC</td>
<td>The International Federation for Clinical Chemistry and Laboratory Medicine</td>
</tr>
<tr>
<td>IT</td>
<td>Information technology</td>
</tr>
<tr>
<td>ISPAD</td>
<td>International Society for Pediatric and Adolescent Diabetes</td>
</tr>
<tr>
<td>PD</td>
<td>Participatory design</td>
</tr>
<tr>
<td>QOL</td>
<td>Quality of Life</td>
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<tr>
<td>QPP</td>
<td>Quality from the Patients’ perspective</td>
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<tr>
<td>SMBG</td>
<td>Self-monitoring of blood glucose</td>
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<tr>
<td>SMS</td>
<td>Short message service</td>
</tr>
<tr>
<td>SWEDIABKIDS</td>
<td>The Swedish pediatric diabetes quality registry</td>
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</tbody>
</table>
INTRODUCTION

Type 1 diabetes is one of the commonest chronic diseases of childhood. When a child or adolescent is diagnosed with diabetes, all of a sudden everyday life involves multiple injections or continuous subcutaneous injection. Blood glucose must be monitored several times a day, and meals and activities must be planned. The blood glucose imbalance must be quickly rectified. Diabetes management affects the life of the child or adolescent, but family, teachers and friends are also involved. In spite of modern insulin treatment, there is a significant risk of long-term complications. In the absence of any effective means of curing type 1 diabetes, the health service has to provide high-quality care. Quality has to be measured from different perspectives if it is to be improved. Quality of diabetes care is usually measured and reported as the level of glycated haemoglobin (HbA1c). In this thesis, the perspectives of the patients and parents are considered, as well as the process and structure of care.

The work of the diabetes team is intended to support children and adolescents and their families through collaboration, education, motivation, and facilitation of life with diabetes, aiming to achieve the best possible blood glucose control, to avoid acute and late complications and to maintain a good quality of life. Patient education is central to this, and the information given to the child and adolescent and to the parents is vitally important. One of the studies in this thesis addresses the message about essential areas of diabetes management given by team members to children/adolescents and parents. In an intervention study, modern information technology was used to enhance patient education and support. I truly hope that some of the findings of this project will help to improve support for children and adolescents with diabetes.
BACKGROUND

Quality of diabetes care

Interest in measuring quality of care has increased in recent years. Stakeholders and healthcare providers are becoming increasingly aware of the importance of quality improvements and of the relationship between quality and safety. The need for cost-effectiveness in health-care has also brought these issues into focus. Health-care needs to be more evidence-based and patient-centred if these demands are to be met 1, 2. In Sweden, quality improvement is governed by legislation, and the Swedish Health and Medical Service Act (SFS 1982:763), available at http://www.sweden.gov.se/content/1/c6/02/31/25/a7ea8ee1.pdf, accessed Jul 8, 2010) stipulates that quality in healthcare should be systematically and continuously developed and assured. Quality measures can be used to identify areas that need improvement, to improve accountability (holding providers responsible for their actions) and to empower informed consumers 3.

The paradigm that underlies the measurement of quality of care is that of Avedis Donabedian 3, 4, who divided quality of care into three structural categories: Structure of care – the relatively stable characteristics of the provider, i.e. equipment, resources, and the physical and organizational settings (e.g. hospital facility, staffing ratios); process of care – what is actually done in the process of giving and receiving care (e.g. patient seeking care, practitioner defining diagnosis, recommending treatment); and outcome – the effect on the health status of the patient (e.g. medical complications, health-related quality of life), patient knowledge, and the level of patient satisfaction. These three domains are interrelated. Simply stated, good structure and process lead to favourable outcomes 5. However, outcomes also depend on a number of other factors beyond the practitioner’s control.

Quality of care has been defined as “fully meeting the needs of those who need the service most, at the lowest cost to the organization, within the limits and directives set by higher authorities and purchasers” 6. This means that patients, staff and healthcare providers must be involved in the process of defining, measuring and improving quality of care.

This project focused on the quality of paediatric diabetes care as seen from the perspectives of children and adolescents, parents and healthcare professionals. The process and structure of
care was addressed in Study IV. Outcomes, measured as patient-perceived quality of care (Studies I and V), health-related quality of life (HRQOL) (Studies II and V), empowerment (Study V) and metabolic control (Studies III and IV) were also investigated.

Metabolic control

Glycated haemoglobin (HbA1c or A1C) is the standard index of glycaemic control over the preceding period of 8-12 weeks. Following the publication of the DCCT study in 1993, several countries developed national standardization programmes, and a system for metrological traceability has been established. All methods used in Sweden are standardized through EQUALIS (External Quality Assurance in Laboratory Medicine in Sweden) and have until this year been traceable to the Mono S method. Swedish values used up to 2010 are approximately 1% lower than DCCT values. According to the consensus statement on the worldwide standardization of the Hemoglobin A1c measurement, a transition to the International Federation for Clinical Chemistry and Laboratory Medicine (IFCC) reference method will be implemented in Sweden in 2010. HbA1c results will then be reported in mmol/mol. Several studies have shown good correlation between HbA1c and blood glucose levels over time.

It is well established that better glycaemic control is associated with fewer long-term complications. Following the DCCT study, the treatment goal of achieving near-normal levels of HbA1c was adopted.

The aims of monitoring glycaemic control, according to The International Society for Pediatric and Adolescent Diabetes (ISPAD) guidelines are:

- To assess the level of glycaemic control achieved by each individual so that they may benefit from attaining their most realistic glycaemic targets
- To help in preventing both the acute complication of hypoglycaemia and the chronic complications of microvascular and macrovascular diseases
- To minimize the effect of hypoglycaemia and hyperglycaemia on cognitive function and mood
- To collect data on glycaemic control from each diabetes centre for comparison with stated local, national and international standards so that the performance and standards of the interdisciplinary Diabetes Care Teams may be improved
However, it is difficult to obtain good metabolic control, especially in adolescents. Many children and adolescents with type 1 diabetes do not achieve adequate HbA1c levels, putting them at risk of complications. Metabolic control deteriorates in adolescence and it is closely linked to metabolic control in late childhood. Several factors (patient-related as well as treatment-related) affect metabolic control. Age, gender, duration of disease, number and frequency of insulin injections, and frequency of self-monitoring of blood glucose (SMBG) have been found to predict metabolic control. Studies have shown that socio-demographic factors such as single-parenthood and lower income, and ethnic minority status in the USA are associated with greater risk for poor diabetes control. Adolescents with diabetes have significantly higher rates of depression than their non-diabetic peers, and researchers have reported that depressed adolescents have poorer metabolic control.

Metabolic control differs between treatment centres, but the reasons for this remain unclear. The differences found in a large cohort in Europe, Japan and North America were followed by feedback and comparison, which led to intensification of insulin therapy in most clinics, but improved glycaemic control in only a few. A recent study suggests that a centre’s effectiveness in implementing treatment regimens appears to influence outcomes. Subsequent findings indicated that the clear and consistent setting of glycaemic targets by diabetes teams is associated with improved outcomes as measured by HbA1c. Differences found in HbA1c between clinics in Scotland could not be explained by factors such as age, insulin regimen, body mass index (BMI), and social circumstances. The authors suggest that structure and strategies of care and clinical philosophy may be determinants of good glycaemic control. Better glycemic control was found in university-affiliated hospitals and centres in a French study. Variables such as public versus private care, socio-economic background, and urban versus rural location were not predictors of glycaemic control in children with type 1 diabetes in New South Wales (Australia) and the Australian Capital Territory.

In this project metabolic control among children and adolescents with diabetes in Sweden and also the differences in mean centre HbA1c is addressed in study III and IV respectively. Furthermore metabolic control is an outcome variable in study V.
Patient satisfaction

Patient satisfaction should be included in evaluations of quality of care because they are partners in healthcare – with perceptions and opinions of their own as to whether care is good or bad. They are the best judges of certain aspects of care, such as interpersonal relations. There are also ideological reasons for their inclusion. In a democratic society, patients should have the right to take part in decisions that influence their lives. In addition, there is a consumer market in healthcare, in which meeting patient need is part of the definition of quality. Furthermore, greater satisfaction has been found to be associated with better compliance. Studies have found that nurses and physicians have different perceptions of quality of care to those of patients.

Only a few measuring instruments have been specifically developed for the assessment of quality of care from the patient's perspective. These include the Quality, Satisfaction, Performance model (QSP), the Quality from the Patient’s Perspective (QPP), and the Picker Patient Experience questionnaire. It has been suggested that the QSP and QPP models could usefully be integrated. The Picker Patient Experience questionnaire identifies problems in healthcare, with lower scores indicating higher satisfaction.

The QPP questionnaire has been used in several studies to assess perceived quality of care in adults. Factors found to be associated with improvement e.g. at an emergency department, included information, respect, empathy, and nutrition. In colostomy patients they included information and patient participation in the decision-making process, and in district nursing care they included pain alleviation and patient participation in the decision-making process. Short waiting time was strongly associated with positive perceived quality of care at an emergency department.

As regards quality of paediatric diabetes care, many studies have been done to assess insulin regimens and biomedical equipment using metabolic control as the outcome variable. Health related quality of life (HRQOL) is also often measured, and validated questionnaires are available. There are validated questionnaires that assess satisfaction with treatment, including the Diabetes Treatment Satisfaction Questionnaire (DTSQ). Modified versions
adapted for adolescents and parents are also available. However, published studies of patient and parent perspectives of paediatric diabetes care are few and far between.

**Health Related Quality of Life**

The demands of diabetes treatment include multiple daily insulin injections, self monitoring of blood glucose, meal planning and physical activities. These have to be coordinated with the social demands of school, family, and leisure activities etc. Consequently, it is important to understand what children and adolescents with diabetes regard as good quality of life, so that we can help them reach this goal whilst simultaneously maintaining good diabetes control. Good quality of life is also a treatment goal and we should therefore measure it. International guidelines recommend that HRQOL should be assessed routinely. It can be measured reliably and prove clinically useful.

The World Health Organization has defined “Quality of Life” (QOL) as “individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” It is a broad concept that is influenced by individual physical and psychological health. Health-related quality of life (HRQOL) reflects the impact of illness and its treatment on an individual’s functions. The key domains of HRQOL include physical, psychological and social function. Generic HRQOL is independent of current health status and is useful in both healthy and chronically ill children, and it allows for comparisons across populations. Disease-specific HRQOL refers to illness-specific outcomes and allows for the assessment of clinically relevant issues within a particular illness group. Such measures of perceived HRQOL are relevant in clinical research and practice and are done to establish patient state (a descriptive perspective), the effects of treatments (a clinical perspective) and for quality assurance (an evaluative perspective).

When HRQOL was compared across eight paediatric conditions, adolescents diagnosed with diabetes reported higher HRQOL than those with eosinophilic gastrointestinal disorder, obesity, and sickle cell disease. They reported lower HRQOL than adolescents with cystic fibrosis, inflammatory bowel disease, epilepsy, and post-renal transplantation. When children and adolescents with 10 different chronic diseases (diabetes, gastrointestinal conditions, cardiac conditions, asthma, obesity, end stage renal disease, psychiatric disorders, cancer, rheumatic conditions, and cerebral palsy) were compared in an earlier study, patients with
diabetes reported the highest HRQOL. In both studies, all children and adolescents with a chronic condition reported lower HRQOL than healthy subjects. Other findings suggest that adolescents with diabetes perceived their HRQOL to be lower than healthy peers. Previous studies of the factors that influence HRQOL in children and adolescents with diabetes have provided generally inconsistent results. There is some evidence that girls rate their HRQOL lower than boys but few researchers have tried to interpret or explain these findings. Some found that younger age was related to higher HRQOL. Higher HRQOL has also been associated with better metabolic control in some studies but the relation is complex and needs further study. Studies of the quality of life benefits of continuous subcutaneous insulin infusion (CSII) have produced conflicting results. Lower HRQOL appears also to be related to higher levels of depression.

Information provided by parents as proxy-respondents is not equivalent to that reported by the child or adolescent. Parents of children with a health condition often perceive HRQOL of their children to be lower than the children do themselves. This indicates that it is important to obtain information directly from children and adolescents.

A variety of questionnaires have been used to assess health-related quality of life in children and adolescents with diabetes. It has been suggested that a combination of generic and disease-specific questionnaires is required for a comprehensive assessment of HRQOL in teenagers.

Empowerment

Empowerment is an important concept in diabetes education and has become an integral part of the process. Diabetes is largely a self-managed disease and the patient’s role is complex and demanding. Empowerment can be defined as “the discovery and development of one’s inherent capacity to be responsible for one’s own life.” Patients are empowered when they have the knowledge, skills, attitudes and self-awareness necessary to improve their quality of life by changing their own behaviour and that of others. Empowerment requires knowledge, and diabetes care teams must provide patients and their parents with the information and skills they need to master their own diabetes care. Changes have occurred in the concept of empowerment since the philosophy was adopted in diabetes care at the beginning of the 1990s. The authors emphasise that health professionals should not make specific
recommendations and solve problems but should instead help patients and their parents to reach their own solutions, making small steps towards the resolution of a greater problem. They conclude that empowerment occurs when the goal of the healthcare professional is to increase the ability of patients to think critically and make autonomous, informed decisions. Empowerment can be described as both a process and an outcome. It is a process when the purpose of educational intervention is to increase the ability to think critically and act autonomously. Empowerment is an outcome when the process results in an enhanced sense of self-efficacy.

**Patient education**

Education is the key to the successful management of diabetes and is central to clinical management. Achieving a balance between insulin levels, food intake and energy expenditure are cornerstones of clinical management. Diabetes requires extensive self-management and frequent high-quality educational input and support. Initial education is about survival, i.e. what the child and the family must learn in order to leave the hospital. This must be followed by education specific to the patient’s individual circumstances. Continuing education involves identifying gaps in theoretical or applied knowledge or barriers to behavioural changes and promoting improved glycaemic control as the main aim. Diabetes education is continuously delivered by healthcare professionals in diabetes care teams at the onset of diabetes, at outpatient clinics, as well as during telephone consultations, group meetings and camps.

The evidence supporting structured educational interventions has been reviewed by several authors. In a review of psycho-educational studies, Murphy et al found that research was improving in both quantity and quality. They concluded that there is still not enough evidence to recommend the adoption of any particular educational programme, and no programme has been proven to be effective in randomized studies of subjects with poor metabolic control. They also found that education appears to be most effective when integrated into routine care, when parental involvement is encouraged, and when adolescent self-efficacy is promoted. It is likely that several different programmes will be required – targeted at different stages, ages and risk groups of individuals, groups and families.

The most commonly used sources of information, as reported by young adults and parents, include diabetes medical teams, diabetes websites, and diabetes associations. Information
technology (IT) and the Internet allow rapid and easy access to sources of information for patients, clinicians, carers and other significant persons. They also allow interactive communication. Results of a review of interactive computer-assisted technology in adults showed improved diabetes health outcomes. It has been suggested that computer-assisted information technology (IT) could be an important tool and should be evaluated for its potential to improve diabetes care. Interventions in children with diabetes have involved a variety of communication methods, including the Internet, telephone, video-conferencing, e-mail, short message service (SMS), and manual downloading of information.

Behavioural management, medication management and physiological (blood glucose) monitoring have been subjects of IT intervention. Few studies have provided definitive evidence, which is not unexpected, as this kind of complex intervention is restricted by methodological limitations.

eHealth

Information technology is developing rapidly and the Internet has become increasingly popular. There is still some uncertainty about how often consumers use the Internet to search for health-related information. By excluding non-health-related search terms, it has been found that 5% of all Google searches are health-related. These data suggest that health information is not one of the most commonly researched topics on the Internet. Nonetheless, given the millions of searches performed each day, they could hardly be described as uncommon. The use of Internet or Web technology in health care is called eHealth.

“Web 2.0” is a term for the second generation of the Internet, referring to improved communication and collaboration between people via social networking. The main difference between Web 1.0 (the first generation) and Web 2.0 is interaction. Web 1.0 was mainly unidirectional while Web 2.0 allows the user to add information or content to the Web.

Examples of user-generated online communities include Facebook, YouTube, Flickr and Twitter. The application of Web 2.0 technology in health and medicine is referred to as Health 2.0 or Medicine 2.0. Examples of such websites include Patientslikeme (Patients Like Me. URL: http://www.patientslikeme.com/ [accessed Aug 3, 2010]) and Hello Health (Hello Health. URL: http://hellohealth.com/ [accessed Aug 3, 2010]). Health 2.0/Medicine 2.0 is still a developing area, and no general consensus regarding the definition of Health 2.0/Medicine 2.0 has been reached. In 2005, the World Health Assembly approved the eHealth resolution which emphasizes the importance of eHealth and asks member states to draw up strategic

A study of patients’ needs as regards Internet interventions in long-term conditions, including adult patients with diabetes and parents of children with diabetes, highlighted the need for further development. It was found that the participants welcomed the potential of Internet interventions but felt that many websites were not achieving their full potential. Participants also generated detailed and specific quality criteria with regard to information content, presentation, interactivity, and trustworthiness, criteria which could be used by developers and purchasers of Internet interventions.

Access to relevant information is the first step to patient empowerment, and it is assumed that Health 2.0/Medicine 2.0 will lead to empowerment of the patient as the Internet can deliver information in vast quantities. The concept of “patient empowerment 2.0” has been described as “the active participation of the citizen in his or her health and care pathway with the interactive use of Information and Communication Technologies”.

An evaluation of an intervention with a web portal with diabetes related information and the possibility to communicate with others with diabetes and health care professionals is presented in this thesis (study V).
HYPOTHESES AND AIMS

As the outcome measured as metabolic control in children and adolescents with diabetes in Sweden is not yet sufficiently good, areas for improvement of care need to be further identified. Thus we hypothesized that perceptions from children’s, adolescents’ and their parents’ perspective reveals areas of improvement as well as groups of patients in need of extra support. Further, we hypothesized that the structure, process, and policy of the diabetes care team, and the attitudes of the team-members, as well as patient education affect metabolic control.

With this background the main objective of this thesis was to gain better understanding of how to improve the quality of diabetes care for children and adolescents, aiming to have near-normal blood glucose, to prevent both acute and late complications and to have good quality of life.

The specific aims of each study were:

- To explore the quality of diabetes care as perceived by children and adolescents on modern treatment and to evaluate the clinical usefulness of the QPP questionnaire for identifying areas needing improvement. The third objective was to study perceived quality of care in relation to factors such as metabolic control and severe hypoglycaemia. (Study I)

- To analyse the impact on health-related quality of life of factors related to the disease and its treatment in intensively treated young patients with type 1 diabetes. (Study II)

- To use detailed registry data to determine how HbA1c is related to duration of diabetes, age, gender and BMI and to assess whether variation in insulin regimens can explain differences in metabolic control. A further aim was to explore differences between mean HbA1c at different paediatric clinics with similar populations. (Study III)
Hypotheses and Aims

- To identify factors for improvement of centre mean HbA1c at paediatric departments treating children and adolescents with diabetes. A further aim was to identify any team characteristics associated with low and high centre mean HbA1c. (Study IV)

- In a clinical experiment develop a web portal with diabetes related information and the possibility to communicate with others, and study its use and effects in young patients with diabetes, and their parents. (Study V)
METHODS

Quantitative and qualitative methods have been used in the studies. An overview of the designs and methods is given in Table 1.

Table 1. Overview of the design, participants, data collection years and methods used in the five studies.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Participants</th>
<th>Data collection period (year)</th>
<th>Data collection method</th>
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</thead>
<tbody>
<tr>
<td>Study I</td>
<td>Observational, Cross-sectional Quantitative</td>
<td>The geographic population of children and adolescents with type 1 diabetes treated at the two paediatric centres in Linköping and Jönköping n=400</td>
<td>2003</td>
<td>Self-completed questionnaire Clinical variables from the Swedish paediatric diabetes quality registry, SWEDIABKIDS</td>
</tr>
<tr>
<td>Study II</td>
<td>Observational, Cross-sectional Quantitative</td>
<td>The geographic population of children and adolescents with type 1 diabetes treated at the two paediatric centres in Linköping and Jönköping n=400</td>
<td>2003</td>
<td>Self-completed questionnaire Clinical variables from the Swedish paediatric diabetes quality registry, SWEDIABKIDS</td>
</tr>
<tr>
<td>Study III</td>
<td>Observational, Cross-sectional Quantitative</td>
<td>Patients &lt; 20 years of age registered in the Swedish paediatric diabetes quality registry, SWEDIABKIDS n=3195</td>
<td>2001-2002</td>
<td>Clinical variables from the Swedish paediatric diabetes quality registry, SWEDIABKIDS</td>
</tr>
<tr>
<td>Study IV</td>
<td>Observational, Cross-sectional Quantitative</td>
<td>Diabetes team members at 15 paediatric centres n=128</td>
<td>2008</td>
<td>Web-based questionnaire Clinical variables from the Swedish paediatric diabetes quality registry, SWEDIABKIDS</td>
</tr>
<tr>
<td>Study V</td>
<td>Randomized controlled intervention study Quantitative</td>
<td>The geographic population of children and adolescents with type 1 diabetes treated at the two paediatric centres in Linköping and Jönköping Eligible 2006: n=474</td>
<td>2006, 2007, 2008</td>
<td>Self-completed Log data from the portal Diabit.se Clinical variables from the Swedish paediatric diabetes quality registry, SWEDIABKIDS</td>
</tr>
</tbody>
</table>
Participants

Study I, II and V
Studies I, II and V included the geographic population of children and adolescents with clinically diagnosed type 1 diabetes treated at the two paediatric centres at Linköping University Hospital and Jönköping County Hospital. Swedish healthcare providers treat all patients in their catchment area, so these populations are unselected.

Data on children and adolescents treated at paediatric clinics are registered in the Swedish paediatric diabetes quality registry, SWEDIABKIDS 79. Studies I and II included all children and adolescents at the two centres registered during 2003, n=400.

All children and adolescents < 19 years of age, treated at the two paediatric centres at Linköping University Hospital and Jönköping County Hospital with a diabetes duration of > 0.1 years, registered during 2005 (n=474) were considered eligible and invited to participate at the start of the intervention study reported in Study V. A further 36 newly diagnosed children were invited to participate after study year 1 (Figure 1).

Characteristics and treatment

Treatment policy consisted of multiple insulin therapy at both centres, following international guidelines 113, and adapted individually. Active self-monitoring of blood-glucose was recommended and patient education and psychosocial support was given by multi-disciplinary diabetes teams. The clinical characteristics of the populations are presented in Table 2.

Table 2. Characteristics of the populations in Studies I, II, and V.

<table>
<thead>
<tr>
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<th>Study I &amp; II</th>
<th>Study V</th>
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<td>n=400</td>
<td>n=474</td>
</tr>
<tr>
<td>Gender, girls/boys (%)</td>
<td>48% / 52%</td>
<td>51% / 49%</td>
</tr>
<tr>
<td></td>
<td>Mean (±SD, range)</td>
<td>Mean (±SD, range)</td>
</tr>
<tr>
<td>Age (years)</td>
<td>13.2 (3.9, 2.6-19.6)</td>
<td>13.2 (3.7, 2.8-18.5)</td>
</tr>
<tr>
<td>Duration (years)</td>
<td>5.1 (3.8, 0.3-17.6)</td>
<td>5.0 (3.7, 0.1-17.7)</td>
</tr>
<tr>
<td>HbA1c (%)</td>
<td>7.1 (1.2, 4.0-10.7)‡</td>
<td>6.8 (1.2, 3.8-12.5) §</td>
</tr>
<tr>
<td>Insulin dose, year mean (U/kg)</td>
<td>0.98 (0.31, 0.19-2.08)</td>
<td>0.96 (0.31, 0.22-2.09)</td>
</tr>
<tr>
<td>Number of daily doses</td>
<td>4.8 (0.7, 2.0-6.7)</td>
<td>5.3 (1.0, 2-10)</td>
</tr>
</tbody>
</table>

‡ Year mean
§ At baseline
Methods

Figure 1. Flow chart of the participants in the intervention and data collection.
Methods

Study III
Study III included all children and adolescents aged < 20 years registered in SWEDIABKIDS, treated at the 22 centres in Sweden that provided data to the registry in 2001 - 2002, n=3195 (1526 girls, 1669 boys).

Study IV
The population in Paper IV consisted of healthcare professionals (diabetes specialist physicians, diabetes specialist nurses, registered nurses, dieticians, physicians under training, psychologists, social workers, healthcare assistants and preschool teachers), n=128, in 15 diabetes teams in Sweden. Between 2003 and 2007 five of these teams had the lowest centre mean HbA1c (Low group), five teams had the greatest decrease in centre mean HbA1c (Decrease group), and five teams had the highest centre mean HbA1c (High group) of the centres in Sweden reporting data to SWEDIABKIDS. Mean HbA1c was 6.8% in the Low group, 7.3% in the Decrease group, and 7.7% in the High group. Two teams were based at university hospitals, four at county hospitals, and nine at smaller local hospitals. Data from the Swedish paediatric diabetes quality registry, SWEDIABKIDS, were used to identify these teams.

Data collection

Questionnaires
Quality of care from the patient’s perspective
A modified version of the questionnaire Quality of Care from the Patient’s Perspective (QPP) was used for data collection 48, 114, 115. The original QPP questionnaire was based on grounded theory. This theoretical model assesses quality of care by measuring both the resource structure of the care organization and the patient’s preferences. Resource structure is made up of person-related as well as physical and administrative environmental qualities. Based on this rationale, the patient’s perception of service quality may be divided into four dimensions: Medical-technical competence of health care professionals, physical-technical conditions of the care organization, identity-oriented approach in the attitudes of healthcare professionals, and the socio-cultural environment of the care organization 48. A questionnaire was developed in which items are evaluated in two ways by the respondents – the perceived quality of care and the subjective importance the patient ascribes to that particular item. The possible

30
responses range from “Do not agree at all” (1) to “Fully agree” (4). When perceived reality is scored lower than importance, patients are considered less satisfied, implying that this area of care is in need of improvement.

The construct validity and the internal consistency have been tested \(^{114,116,117}\). Using our clinical experience, we selected for our study the items in the QPP questionnaire that we thought suitable for adolescents with diabetes and for parents of children and adolescents with diabetes. Diabetes-specific items were added. The dimensions, factors and number of questions in both the modified version and the original QPP questionnaire are shown in Table 3.

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Factor</th>
<th>Number of items in the modified QPP</th>
<th>Number of items in the original QPP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical-technical competence</td>
<td>Medical care</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Treatment waiting time</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Physical-technical conditions</td>
<td>Medical technical equipment</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Identity-oriented approach</td>
<td>Information before procedures</td>
<td>2 (4)*</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Information after procedures</td>
<td>15 (30)*</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Participation</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Contact person</td>
<td>2 (4)*</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Respect, all professions</td>
<td>15</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Commitment, all professions</td>
<td>15</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Empathy, all professions</td>
<td>10</td>
<td>6</td>
</tr>
<tr>
<td>Socio-cultural environment</td>
<td>General atmosphere</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Privacy</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Routines</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Context-specific items</td>
<td>Continuity in patient-doctor relation</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Advice and instructions</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Access to care, diabetes doctor</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Access to care, diabetes nurse</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Waiting time at the outpatient clinic</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

* Numbers of items in the questionnaire for parents
Health-related quality of life

The Disabkids questionnaire was used to measure HRQOL in Studies II and V. The Disabkids project, a cross-cultural multi-centre study in seven European countries, developed a HRQOL questionnaire for children and adolescents with a chronic medical condition, in self-completion and proxy versions. The reliability and validity of the questionnaire have been established. The DISABKIDS generic module includes six subscales: Physical limitation, emotion, independence, social inclusion, social exclusion, and treatment. Disease-specific modules for different chronic conditions are available. The module for diabetes consists of two domains of diabetes QOL, the burden of treatment, and impact of treatment on emotional reactions. Low values reflect low QOL, on a 5-point Likert scale.

The Disabkids generic module is available in a long 37-item version and a short 12-item version. As Study II was carried out during the development phase of the short form, a pilot version of the short form was used. This was provided by the Disabkids group and included 19 items. In Study V, the final 12-item version of the short form was used. The final version of the diabetes-specific module was used in both Study II and Study V.

The Disabkids instrument has now been used in several surveys of children with chronic health conditions, e.g. limb reduction deficiency, diabetes, urinary incontinence, asthma, neurofibromatosis, and cancer.

Empowerment

The Swedish Diabetes Empowerment scale short form (SWE-DES-SF-10) was used to assess empowerment in Study V. It reflects four subscales: Goal achievement, self-awareness, stress management, and readiness to change. The scores range from strongly agree (=5) to strongly disagree (=1).
instrument has been validated for adults but not for children or adolescents \cite{ref131} although it has been used previously in studies of adolescents \cite{ref132}.

**Process, structure, and treatment policy**

A questionnaire was constructed covering key issues in diabetes treatment and care, based on the hypothesis of Study IV and the author’s best clinical practice. Health professionals from the 15 included diabetes teams were asked to report data on process, (e.g. treatment at diagnosis, insulin treatment, routines for patient education, frequency of outpatient attendances, process of work within the team, and follow-up of centre results), structure (e.g. centre size, team size, paediatric and diabetes education, and professional experience) and policy (e.g. HbA1c target value and guidelines for interventions at different levels of HbA1c). Open-ended questions were used to obtain a deeper understanding of team policy, attitudes of team members and the message conveyed to patients and parent, e.g. “As regards life / diet / physical activity etc., what is the most important message you would like to convey to children/adolescents with diabetes and their parents?” Finally respondents were asked to “Give reasons for the mean HbA1c at your centre”.

**Questionnaire administration procedure**

The questionnaires in Studies I, II and V (including a stamped return envelope) were sent from an independent department at Linköping University. Two (Studies II and V) or three reminders (Study I) were sent to the respondents.

In Study IV a web-based questionnaire was e-mailed to each member in the diabetes teams included in the study (three reminders). The e-mail addresses were obtained from a contact person in each team when the team accepted our invitation to join the study.

**Clinical variables**

Outpatient attendance data from Swedish paediatric diabetes centres are registered in the Swedish paediatric diabetes quality registry, SWEDIABKIDS \cite{ref79}. Initially, from 2000 to 2007, data were registered locally in a specially designed program for childhood diabetes. The registry has been web-based since 2008 and is available to all paediatric diabetes centres in Sweden. In Study III, all the data in the analysis were obtained from this registry. In Studies I, II, and V the registry was the source of data on age, HbA1c, duration, insulin dose, number of insulin injections and insulin treatment. In Study IV data on HbA1c and insulin dose were provided by the registry.
HbA1c

HbA1c, expressed as the percentage of haemoglobin that is glycated reflects average blood glucose levels during the preceding 8-12 weeks \cite{9,15,133-135} and is the gold standard for long-term follow-up of glycaemic control. The data on HbA1c obtained from SWEDIABKIDS, were derived from capillary blood samples measured with the Bayer/Siemens DCA-2000 analyzer or by local laboratory methods. All methods were standardized through EQUALIS (External Quality Assurance in Laboratory Medicine in Sweden) and were traceable to the Mono-S method. At the time that the studies in this thesis were carried out, Swedish HbA1c values used were on average 1% lower than values produced by the Diabetes Control and Complication Trial (DCCT)/National Glycohemoglobin Standardization Program (NGSP) \cite{13}. The normal range at age < 50 years was 3.6-5.0%. The 2007 ISPAD guidelines divides HbA1c levels into three categories: < 6.5% (optimal), 6.5-8% (suboptimal, action suggested), > 8% (high risk, action required) \cite{136}.

Web portal log data

A personal password was required to access the web portal during the two study periods in Study V. Logged data were continuously stored on a server at Linköping university, and they were analysed for frequency and temporal pattern of login and page hits.

Web portal intervention

Development

The web portal was developed in collaboration with medical informatics researchers, paediatricians, behavioural scientists, clinicians, patients and their parents \cite{137,138} using participatory oriented design (PD) \cite{139}. The design specification was developed in steps. The inter-operability of system functions was refined after evaluations by clinical staff, children and parents. The development process has been described by Ekberg et al \cite{137} and started with interviews, cultural probes method \cite{140} and workshops to identify the needs and requirements of children and adolescents with diabetes. The collected data were validated and evaluated by testing prototypes. After further analysis, a system solution was defined.
In the spring of 2006, the research group and the two participating diabetes teams launched the Internet portal, called Diabit, for invited patients and parents.

Content
The Diabit portal contained specific diabetes-related information and social networking functions such as message boards and blogs. The content of the portal was designed for the children, parents, and practitioners of the local communities of the two respective hospitals. For younger children, the portal was targeted at their parents, and for children aged 12 years and over, the portal was designed to appeal to both parents and adolescents. There was a set of rules for using the community areas of the portal, based on common sense and national laws, with individual users being responsible for the information they provided.

Extensive information was provided in text pages, short educational films and online simulation software. Information for doctors was evidence-based and relied on best clinical practice to try to create trusted and reliable sources of information. Specific diabetes-related information on 13 main topics, divided into 99 subtopics/web pages, had been written by members of the two local diabetes teams. Links to diabetes-related information included Acute situations, What is diabetes, Relationships, Late complications, Insulin, Devices, Food, Blood glucose, Exercise and sports, Living with diabetes, This can affect, Research and External links. Each section was revised by other team-members from the two hospitals. The names and affiliations of the authors and editors of the text were displayed at the bottom of the screen, with the date of the latest update (Figure 2).
The portal also provided functions for repeat prescriptions, making appointments, asking questions, viewing questions and answers, contact information, photos of staff, and other general information about the local diabetes teams and their services. In addition, each local diabetes team provided a personalised summary of important basic information, e.g. “What I might say to newly diagnosed children and their parents”.

**Design of the intervention**

The flow of participants and follow-up is presented in Figure 1. Children and adolescents with diabetes treated at the paediatric clinics in Linköping and Jönköping were randomized either to the intervention group or the control group. The intervention group gained access to the web portal at the start of the first study period in year one (April 2006), using a personal password. Subjects in the control group were offered a personal password after the first study period.

The first study period started in April 11, 2006 and was planned to last 12 months but, due to the slow inclusion of active users, it was extended to September 25, 2007. The second study period, year two, lasted from September 26, 2007 until September 25, 2008.
Surveys were conducted at baseline, after study year one and after study year two. Logged data from the portal were registered continuously. Clinical variables were registered in SWEDIABKIDS at outpatient attendances during the study periods and included in the analysis.

**Quantitative data analyses**

All analyses were performed using the SPSS program, version 10.0-17.0. A p-value of $< 0.05$ was considered statistically significant. Student’s t-test was used when data were normally distributed. Student’s t-test (one-way) was used for comparison of a group mean value to grand means in Studies I and II and Student’s t-test (independent) was used for comparisons of mean values between different groups. The Mann-Whitney U test was used for comparisons between groups when data were not normally distributed. Mean values before and after the intervention in Study V were compared using Student’s paired test (normally distributed data) and the Wilcoxon signed rank test (non-normally distributed data). Categorical variables were compared by Chi-square test. Correlations were assessed with Pearson’s correlation. ANOVA was used for comparisons between multiple variables. Stepwise multiple linear regression analysis was done to identify predictor variables of HRQOL and HbA1c in Study II and Study III respectively. Reliability and internal consistency in factors in Study I were measured by using Cronbach’s alpha.

**Active users of the web portal**

In a separate analysis before and after the first year of access, active users were defined as those where someone in the family logged in five times or more during their first year with access to the portal. This cut-off level for active use was defined retrospectively taking into account the distribution of frequency of use. The group of active users were compared to those with zero to four site visits during the same time period. Thus we merged data for the intervention group at baseline and after one year only (study year one), and for the previous control group before and after one year of access respectively (study year two).
Qualitative data analysis

The open-ended questions in Study IV were analysed by summative content analysis. Researchers were blinded to hospital groups. The written answers were reviewed by the main author and a co-author. The analysis began with the identification and quantification of certain words or phrases in the text. Next, these words or phrases were categorised according to their perceived meaning. A latent content analysis was then carried out, with the aim of capturing the meaning of each category. Latent content analysis is a term for the process of interpretation of content with the aim of discovering underlying meanings of words or phrases. This analysis was performed independently by the main author and co-author. Categorisations were compared and reviewed until consensus was reached.

Ethics

The studies were approved by the Research Ethics Committee of the Faculty of Health Sciences at Linköping University, Sweden.

The participants in Studies I and II were given written information about the studies. They were informed that participation was voluntary, that data would be treated confidentially and that the findings could not be traced back to specific individuals, which meant that patient and parent responses to the questionnaires about perception of quality of care and HRQOL could not affect care provision.

Parents and adolescents were given written information about the registration of data in the SWEDIABKIDS at the time of diabetes diagnosis, and they gave written consent to registration of data in this registry. Values registered in the quality registry were generated during routine clinical consultations and did not involve any extra measurements.

The participants (both parents and adolescents) in the web portal intervention study were given written information. They were informed that they could withdraw from the intervention at any time without giving a reason. Parents and adolescents gave written consent to participate. Diabetes team members did not have access to the message board in order to provide a secure and comfortable environment for the patients and parents who formed this community.
The rules for the community areas (message board and blogs) were listed on the web portal along with information about the user’s personal responsibilities. One researcher was assigned the role of message board moderator with the task of monitoring postings and removing inappropriate content.
RESULTS

Quality of care from the patient’s perspective (Study I)

The results indicated high perceived quality in general in both parents and adolescents. Figures 3 and 4 show the highest and the lowest ranked factors as measured by mean perceived reality along with the ascribed importance of each, in adolescents and parents. In both parents and adolescents, discrepancies were found between perceived reality and importance for the factors:

- information about self-care
- waiting time at the outpatient clinic
- treatment waiting time
- access to care

Parents generally rated reality significantly higher and importance even higher than adolescents did. Grand mean for reality in parents and adolescents was 3.35, SD ±0.46 and 3.27, SD ±0.45 respectively (p=0.012). Grand mean for importance in parents and adolescents was 3.67, SD± 0.36 and 3.42, SD± 0.46 respectively (p<0.001).
Results

Figures 5 and 6 show items within the factor of information about self-care. Differences between reality and importance were found in information provided about:
- alcohol
- late complications
- prevention of complications
- prevention of ketoacidosis
- infections

Figure 5. Grand mean for perceived reality and importance in parents for items within the factor of information about self-care. Arrowed items show a discrepancy between perceived reality and importance.

Figure 6. Grand mean for perceived reality and importance in adolescents for items within the factor of information about self-care. Arrowed items show a discrepancy between perceived reality and importance.

Grand mean of reality in parents reporting that their child had had severe hypoglycemia (needing help from another person) during the last year (n=101) was lower than in those reporting that their child had not had severe hypoglycemia during the same period (n=110) (3.18 SD ±0.47 v. 3.41 SD ±0.44, p<0.001). No correlation was found between HbA1c, insulin dose, number of doses, age, duration or BMI and the grand mean of factors for either perceived reality or importance.
Less satisfied subjects

Less satisfied subjects were defined as those who reported a mean reality lower than the grand mean combined with a mean importance higher than the grand mean. HbA1c was higher in the less satisfied subjects than in all other subjects (7.3%, ±SD 1.2 v. 6.9%, ±SD1.2, p = 0.037).

Health-Related Quality of Life (Study II)

Parents and adolescents reported lower HRQOL for diabetes-specific parameters (dimensions not included in the questionnaire for children 8-12 years) than for generic parameters.

Diabetes-specific HRQOL in adolescents correlated inversely with HbA1c, as did generic HRQOL in boys aged 8-12 years.

Differences between groups regarding generic HRQOL and diabetes-specific HRQOL are shown in Table 4. Higher generic and diabetes-specific HRQOL scores were found in parents of adolescents who reported that their child had not had severe hypoglycemia during the previous year than in those who reported that their child had suffered severe hypoglycaemia during the same period, but this difference was not seen in the adolescents’ own reports. The pattern was the same in parents of children aged 8-12 years. This pattern was repeated in the EQ-5D scores of parents of adolescents. Generic HRQOL in adolescents correlated with the number of insulin doses (Table 5).

A gender difference was found in that adolescent girls reported a lower grand mean of generic and diabetes-specific parameters compared to boys. Parents of girls aged < 8 years reported lower grand means of diabetes-specific parameters than parents of boys aged < 8 years. Adolescents and children aged 8-12 years reported higher grand means of GeHRQOL than did their parents.

Adolescents with parents living together reported higher generic and higher diabetes-specific HRQOL than those with separated parents.
Both GeHRQOL and DiHRQOL were inversely correlated with self-estimated degree of disease severity in adolescents, parents of adolescents, and parents of children aged 8–12 years (Table 5). The same was found for frequency of diabetic problems in adolescents, parents of adolescent, and parents of children aged 8–12 years. EQ-5D in both adolescents and their parents was inversely correlated with the degree of disease severity. EQ-5D was also inversely correlated with the frequency of diabetic problems, in adolescents and in their parents.

Table 4. Differences in generic HRQOL (GeHRQOL) and diabetes-specific HRQOL (DiHRQOL) between groups.

<table>
<thead>
<tr>
<th></th>
<th>GeHRQOL</th>
<th></th>
<th>DiHRQOL</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean, SD</td>
<td>p</td>
<td>Mean, SD</td>
<td>p</td>
</tr>
<tr>
<td>Parents of adolescents:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>child not had severe hypoglycemia</td>
<td>80.8, ±11.2</td>
<td>0.014</td>
<td>60.2, ±15.4</td>
<td>0.047</td>
</tr>
<tr>
<td>child had severe hypoglycaemia</td>
<td>75.9, ±12.4</td>
<td></td>
<td>55.9, ±16.3</td>
<td></td>
</tr>
<tr>
<td>Parents of children aged 8-12 years:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>child not had severe hypoglycemia</td>
<td>82.9, ±10.0</td>
<td>0.005</td>
<td>62.6, ±14.1</td>
<td>0.007</td>
</tr>
<tr>
<td>child had severe hypoglycaemia</td>
<td>75.9, ±12.5</td>
<td></td>
<td>53.0, ±17.8</td>
<td></td>
</tr>
<tr>
<td>Adolescent girls</td>
<td>79.5, ±12.0</td>
<td>0.041</td>
<td>53.5, ±19.8</td>
<td>0.001</td>
</tr>
<tr>
<td>Adolescent boys</td>
<td>83.4, ±11.3</td>
<td></td>
<td>63.9, ±17.6</td>
<td></td>
</tr>
<tr>
<td>Parents of girls aged &lt;8 years</td>
<td></td>
<td></td>
<td>58.7, ±11.5</td>
<td>0.047</td>
</tr>
<tr>
<td>Parents of boys aged &lt;8 years</td>
<td></td>
<td></td>
<td>68.0, ±12.5</td>
<td></td>
</tr>
<tr>
<td>Adolescents</td>
<td>81.5, ±11.8</td>
<td>0.019</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents of adolescents</td>
<td>78.7, ±12.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children aged 8-12 years</td>
<td>82.7, ±11.7</td>
<td>&lt;0.001</td>
<td>60.9, ±18.0</td>
<td>0.047</td>
</tr>
<tr>
<td>Parents of children aged 8-12 years</td>
<td>78.6, ±12.0</td>
<td></td>
<td>46.7, ±24.2</td>
<td></td>
</tr>
<tr>
<td>Adolescents with parents living together</td>
<td>82.8, ±10.4</td>
<td>0.027</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adolescents with separated parents</td>
<td>71.7, ±14.9</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 5. Variables that correlate with EQ-5D, Generic HRQOL (GeHRQOL) and Diabetes-specific HRQOL (DiHRQOL) in different groups.

<table>
<thead>
<tr>
<th></th>
<th>HbA1c</th>
<th>Insulin dose frequency</th>
<th>Disease severity</th>
<th>Frequency of problems with the diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>r</td>
<td>p</td>
<td>r</td>
<td>p</td>
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<tr>
<td>Boys aged 8-12 years:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GeHRQOL</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-0.28</td>
<td>0.045</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adolescents:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GeHRQOL</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0.24</td>
<td>0.007</td>
<td>-0.39</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>DiHRQOL</td>
<td></td>
<td></td>
<td>-0.42</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>EQ-5D</td>
<td></td>
<td></td>
<td>-0.41</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Parents of adolescents:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GeHRQOL</td>
<td></td>
<td></td>
<td>-0.39</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>DiHRQOL</td>
<td></td>
<td></td>
<td>-0.49</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>EQ-5D</td>
<td></td>
<td></td>
<td>-0.46</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Parents of children 8-12 years:</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>GeHRQOL</td>
<td></td>
<td></td>
<td>-0.47</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>DiHRQOL</td>
<td></td>
<td></td>
<td>-0.53</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

A multiple linear regression analysis was done on the effect of different variables on generic HRQOL, diabetes-specific HRQOL and EQ-5D in the different groups. The following variables each accounted for 2-18% of reported HRQOL:

- gender
- age
- duration
- HbA1c
- recent severe hypoglycaemia
- frequency of blood glucose tests
- parents living together or not
- mother’s educational level
- use of insulin pump
- centre

Different patterns were found in parents, adolescents and in children aged 8-12 years.
HbA1c in children and adolescents with diabetes (Study III)

**Metabolic control**

For the patients registered in the Swedish paediatric diabetes quality registry, SWEDIABKIDS, during 2001-2002, the 2-year overall mean HbA1c was 7.5% (±SEM 0.1, n=2160), DCCT / NGSP-corrected 8.3%, and values were normally distributed. HbA1c for girls (all ages) was 7.5 (SD 1.3, range 3.7-13.7, n=1022) and boys 7.4 (SD 1.2, range 4.2-14.5, n=1138) (p=0.015). Glycaemic control deteriorated with increasing age, with significant differences becoming apparent between boys and girls in adolescence, at the ages of 14, 16, 17, and 18 (Figure 7).

35% of children and adolescents had mean HbA1c values of < 7.0% (our target value during the data collection period) (Figure 8).

---

**Results**

- HbA1c values in boys and girls. P value of the difference between boys and girls at the ages of 14, 16, 17 and 18 (*p<0.05, **p<0.01, ***p<0.001).
- Distribution of HbA1c into four HbA1c categories.
Results

Diabetes duration correlated with mean HbA1c ($r= 0.248$, $p<0.001$), as did higher age ($r= 0.222$, $p<0.001$). However, no correlation was found between HbA1c and age- and gender-adjusted BMI SD.

In children who had had diabetes for more than 4 years, there was a weak correlation between duration and 2-year mean HbA1c ($r=0.130$, $p<0.001$).

**Insulin regimen**

Age correlated with mean insulin dose expressed as U/kg/day ($r=0.263$, $p<0.001$). The correlation between mean insulin dose and disease duration ($r=0.238$, $p<0.001$) was more evident in boys ($r=0.316$) than in girls ($r=0.155$).

**Metabolic control and insulin regimen**

HbA1c correlated with mean insulin dose expressed as U/kg body weight ($r=0.341$, $p<0.001$). Insulin dose varied between the four categories of HbA1c ($p<0.001$), with the highest being seen in those with the highest HbA1c.

**Centres**

As shown in Figure 9, mean HbA1c varied between centres, from 6.8% (95% CI 6.77-6.91) to 8.2% (95% CI 8.09-8.28), ($p<0.001$). Of the 20 centres, only one reported a mean HbA1c below our target value (7.0%) at the time of data collection, and one centre was just above (7.1%). The numbers of attendances at the centres did not correlate with the centre mean HbA1c. The mean insulin dose varied between centres, from 0.92 U/kg/day (95% CI 0.86-0.97) to 1.12 U/kg/day (95% CI 1.04-1.20), $p<0.001$. The mean insulin dose or duration of diabetes for each centre did not correlate with the centre mean HbA1c. Gender, insulin dose, number of doses, age, duration, the age- and gender-adjusted BMI SD, and the number of patients did not differ between the centres with the five lowest and those with the five highest mean HbA1c.
In a multiple regression model that included age, gender, duration of diabetes, insulin dose, and age- and gender-adjusted BMI SD, high insulin dose (beta coefficient 1.09, p<0.001) followed by high number of visits per patient year (beta coefficient 0.14, p<0.001), long diabetes duration (beta coefficient 0.05, p<0.001) and age (beta coefficient 0.02, p<0.001) were found to be significant predictors of raised HbA1c. BMI SD was not a statistically significant predictor of raised HbA1c (beta coefficient 0.01, p=0.329). This pattern was more obvious in girls than in boys for insulin dose (beta coefficient 1.43, p<0.001), diabetes duration (beta coefficient 0.4, p<0.001) and age (beta coefficient 0.04, p<0.001). As expected, mean HbA1c varied significantly between centres (p<0.001) (Figure 10). In the regression model, this difference remained significant after adjusting for age, gender, duration of diabetes, insulin dose, and age- and gender-adjusted BMI SD. This pattern remained when only children of pubertal age were included.
Centre Mean HbA1c – Process, Structure and Policy (Study IV)

Similarities were found in the Low and the Decrease groups. Differences in structure, process, and policy between these two groups compared to the High group are presented below.

Differences in structure:
- Shorter length of professional experience of team members. Means, in years, were 17.8 (range 15.4-21.8), 15.4 (range 14.9-27.4), and 23.1 (range 20.6-30.0) for the Low, Decrease, and High group respectively.
- Lower proportion of team members with special paediatric education (54%, 53%, and 65% for the Low, Decrease, and High group respectively) and, similarly, diabetes education (24%, 30%, and 34% for the Low, Decrease, and High group respectively).
- Lower proportion of team members who perceived that the team leader did not meet their expectations (11%, 15%, and 32% in the Low, Decrease, and High group respectively).
- A trend for larger centre size (more patients). The numbers of patients treated were > 100 at 4, 5, and 3 of the centres in the Low, Decrease, and High group respectively.
- A trend for larger team size. The numbers of diabetes team members were > 5 at 5, 5, and 3 of the centres in the Low, Decrease, and High group respectively. There was no difference in ratio of patients to diabetes team member.

Differences in process
- Higher frequency of teams with mean insulin dose above the grand mean for all Swedish paediatric centres (3 teams, 4 teams, and no team in the Low, Decrease, and High group respectively).
- Higher compliance to guidelines on action to be taken at HbA1c levels above target value. The proportion of team members stating that guidelines were always or often followed were 51%, 46%, and 27% in the Low, Decrease, and High group respectively.

Differences in policy
- A trend for lower HbA1c target value. Target value was 6% in 1 and 2 teams in the Low and Decrease groups respectively, but this was not reported by any of the teams.
in the High group. Target value was 6.5% in 4, 3, and 5 of the teams in the Low, Decrease, and High group respectively.

**Attitudes and policy among team members**

The results of the analysis of the open-ended questions about the message conveyed to patients and parents about important issues in diabetes management are presented in Table 6. Similarities were found between the Low and the Decrease groups. The most frequently reported messages in the groups are shown in Table 6. The Low and the Decrease groups are compared with the High group.

Table 6. The commonest messages from the diabetes team members to patients and parents about important issues in diabetes management.

<table>
<thead>
<tr>
<th>Issue</th>
<th>Low and Decrease group</th>
<th>High group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life with diabetes</td>
<td>Diabetes changes life but life can still be good. Planning and regularity was emphasized.</td>
<td>Diabetes does not cause a big change in life, and life will almost stay the same. You have to learn to accept the disease and you will need knowledge. Good quality food, without being specified, and eaten at regular times.</td>
</tr>
<tr>
<td>Diet</td>
<td>Good quality food, without being specified, food everyone should be eating. Planning and regularity was emphasized.</td>
<td></td>
</tr>
<tr>
<td>Sweets</td>
<td>Sweets are acceptable, but should only be eaten on rare occasions.</td>
<td>Reduction if there is visible sugar was (one respondent).</td>
</tr>
<tr>
<td>Physical activity</td>
<td>Physical activity is good and should be encouraged. Physical activity is important; it is a part of the treatment and makes the management of diabetes easier. Planning and regularity was emphasized.</td>
<td>Physical activity is good and should be encouraged. Diabetes is not an obstacle to physical activity.</td>
</tr>
<tr>
<td>Self monitoring of blood glucose</td>
<td>Self-monitoring of blood glucose is required for good metabolic control and has to be interpreted and analysed. High frequency of blood glucose tests was recommended (2-6 tests / day, day profiles every week).</td>
<td>Self-monitoring of blood glucose is required for good metabolic control and has to be interpreted and analysed. Low frequency of tests was recommended (2 tests / day, day profiles every 3rd month).</td>
</tr>
<tr>
<td>Adjustment of insulin doses</td>
<td>Parents and children are encouraged to adjust insulin doses by testing and evaluation.</td>
<td>Parents and children are encouraged to adjust insulin doses by testing and evaluation. A higher proportion in this group stated that you learn to adjust doses in time.</td>
</tr>
<tr>
<td>Treatment of hypos</td>
<td>Dextrose is usually enough to reverse hypoglycaemia and the patient should not eat too much.</td>
<td>Quick action was recommended in the event of hypoglycaemia, treated with food or dextrose, depending on the situation.</td>
</tr>
<tr>
<td>Prevention of hypos</td>
<td>Information was given about acute complications and how to prevent and treat them. Some said that mild hypos are not dangerous.</td>
<td>Information was given about acute complications and how to prevent and treat them.</td>
</tr>
<tr>
<td>Prevention of late complications</td>
<td>Good metabolic control reduces the risk of late complications, a message used to encourage treatment concordance.</td>
<td>Good metabolic control reduces the risk of late complications, a message used to encourage treatment concordance. Information was given about tobacco as a risk factor.</td>
</tr>
<tr>
<td>HbA1c</td>
<td>HbA1c reflects blood glucose levels over the previous weeks and the target value is 6.5%. Many in the Decrease group gave 6% as target value.</td>
<td>HbA1c reflects blood glucose levels over the previous weeks and that the target value is 6.5% but that the target value could also be individual.</td>
</tr>
</tbody>
</table>
The perceptions of reasons for centre mean HbA1c in the Low and the Decrease group demonstrated a positive attitude to the team and a feeling of involvement (Table 7). Team members expressed reasons for failure in the High group.

Table 7. Most frequently reported reasons for centre mean HbA1c in the Low, Decrease, and High group respectively.

<table>
<thead>
<tr>
<th>Reasons for centre mean HbA1c</th>
<th>Low</th>
<th>Decrease</th>
<th>High</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cohesive team</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Team members give the same message</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Team members are focused on treatment targets</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Patient follow-up</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Patient information</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Team members are highly involved</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Team members are accessible</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information and care at diagnosis</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High competence of team members</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of resources</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of cooperation within the team</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of treatment guidelines</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Guidelines need to be revised</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Characteristics of the population</td>
<td>X</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

What does this mean?
Greater clarity in the message conveyed to patients and their families was found in the Low and Decrease groups compared to the High group.

This was shown for
- HbA1c target value (most obvious in the Decrease group)
- Diet, physical activity and the treatment of hypoglycaemia
- Structured everyday life
- Diabetes requires that life must be lived within certain limits in diet, physical activity and self-treatment.

Another difference was that team members in the Low and Decrease group displayed a high degree of commitment and engagement in the way they formulated their answers. This was reflected in their frequent use of capital and italic letters and exclamation marks. This was
also suggested by their different choice of words. In the context of physical activity positive expressions were found in the Low and Decrease groups, e.g. “…daily physical activity which is nice and fun…”, “…great to be active physically”, “It’s great for the disease and the body”, while this type of expression did not feature at all in the High group.

The perception of reasons for centre mean HbA1c revealed feelings of self-confidence and success, with a positive attitude to the team and the task in the Low and Decrease groups, while the opposite was shown in the High group.

**Use of a web 2.0 portal to improve education and communication in young diabetes patients with families – a case study (Study V)**

The most frequently visited pages of the portal in study year one were the social networking features such as blogs, stories and discussions, followed by the diabetes team pages and an online disease simulator device.

No differences were found at baseline, after study year one, or after study year two between the intervention and the control group, in either adolescents or parents, as regards the outcome variables (HRQOL, empowerment, perception of quality of care regarding information measured by DISABKIDS, SWE-DES-SF-10 and QPP, HbA1c, frequency of severe hypoglycaemia, and frequency of glucose self-monitoring). No difference was found in Internet use (aims of using, contact with others with diabetes, and searching for information about diabetes).

Active users (those with a family member who logged in 5 or more times during the first year of access to the portal), n=68, compared to those who were less active (n=419) were younger (mean age 12.1 years, ±SD 3.8 v. 14.0 ±SD 3.8, p=0.008), had shorter diabetes duration (mean years 3.9, ±SD 3.3, v. 5.5, ±SD 3.8, p= 0.006), and had lower HbA1c (mean 6.4%, ±SD 1.1, v. 6.8%, ±SD 1.2, p=0.010).

The proportion of girls was higher in the active user group than in the comparison group (p=0.001). More mothers than fathers were active users but the difference was not statistically
significant. Seven active users (10%) had HbA1c > 8%, which was comparable to the comparison group (56/419, 13%), p=0.535.

In active users, no differences were found between baseline and after intervention, in HRQOL, empowerment, or the perceived quality of information. HbA1c, insulin dose, frequency of glucose self-monitoring, number of injections per day, and number of severe hypoglycaemia attacks in the previous 12 months did not differ between the groups.
DISCUSSION

The development and improvement of quality of care involves changing attitudes, values, protocols and processes. Changes must be evidence-based, which requires research. The definition of quality of care, as mentioned in the introduction, implies that the perspectives of both patient and professional have to be taken into account\(^6\), as this thesis has done.

The main findings are presented below in relation to the aims, followed by a discussion based on Donabedian’s classification of quality of care: Structure, process and outcome. Methodological issues are also addressed.

**Main findings**

Overall quality of care as perceived by patients and parents was high. Specific parts of care that were considered to be in need of improvement included information about self-care, waiting time at outpatient clinics and for treatment, and access to care. Those who were less satisfied had poorer metabolic control than those who were more satisfied.

Diabetes seems to reduce HRQOL. Subjects with better metabolic control and on intensive insulin treatment with higher numbers of injections did report somewhat higher HRQOL, as did those living with both parents compared to those with separated parents.

Only 35% of children and adolescents with diabetes in Sweden had an HbA1c level below the treatment target value. Mean HbA1c showed a correlation with mean insulin dose, diabetes duration, and age. A pronounced difference between centres was found, but this could not be explained by differences in insulin dose, diabetes duration, or age.

A gender difference was found in HRQOL and metabolic control. Adolescent girls reported lower HRQOL, as did parents of girls aged < 8 years. Girls also had poorer metabolic control, especially during adolescence.

Diabetes care teams at centres with low centre mean HbA1c had a lower HbA1c target value than centres with high mean HbA1c. They also provided a clearer message to patients and their families about diet, physical activity, treatment of hypoglycaemia, and structured everyday life. Members of these teams showed greater commitment and had a positive
attitude to the team, reporting that team members collaborated well. Team members at centres with high mean HbA1c gave a vaguer message and perceived a lack of collaboration within the team. High insulin dose, large centre population, and high numbers of team members also seem to characterize diabetes centres with low mean HbA1c.

The most frequently visited pages on the web portal were the social networking pages, such as blogs, stories and discussions, followed by the diabetes team pages. Those who used the portal most actively were younger, had shorter diabetes duration, and lower HbA1c, although those with HbA1c > 8% were also found in this group of active users. A gender difference was found, with girls and mothers visiting the portal more frequently than boys and fathers. The web portal was not found to have any significant beneficial or adverse effects on HRQOL, empowerment or metabolic control.

Structure of care

There is a long tradition of working in multi-disciplinary diabetes care teams. The DCCT study concluded that this had beneficial effects on patients’ metabolic control\(^\text{10}\). The patients included in the present studies were all treated by teams that included several professions. In Study IV, teams with low centre mean HbA1c tended to treat more patients, but no significant correlation between centre population (numbers of patients treated) and centre mean HbA1c was found, which is consistent with previous studies \(^\text{7}\). These teams also had more members, although the ratio of patients to team members did not differ. Some studies have found that larger teams are more effective, whereas other studies have reported that larger teams suffer from coordination and process inefficiencies. Taken as a whole, results suggest that the benefits of larger teams are dependent on the nature of the task and the team environment \(^\text{143}\). The shorter formal education and shorter diabetes working experience found in the Low and Decrease group could be explained by the possibility that commitment and enthusiasm may decline with increasing length of service in the same role. The leader in a team has an important role \(^\text{144}\). He or she has to have the ability to clarify goals, and to motivate and encourage team members to work towards these. In teams with high centre mean HbA1c, a higher proportion of team members expressed dissatisfaction with the leadership. The High group also reported a lack of collaboration within the team which could also reflect poor leadership.


Discussion

Process of care

Treatment at the time of diagnosis was similar at all centres included in Study IV and followed Swedish national guidelines \(^{145}\). The methods and materials that were used for patient education were roughly the same, and no specific method was found to be more successful, which is consistent with the findings of others \(^{85}\).

In the population of 2,160 patients in Study III, insulin dose correlated with HbA1c, and this was more evident during adolescence, indicating that there are other physiological and psychological factors that influence metabolic control. High insulin dose was also among the strongest predictors of high HbA1c level, but it can be reasonably assumed that insulin dose is increased as the HbA1c level increases. On the other hand, centre mean insulin dose tended to be higher at centres with low centre mean HbA1c in Study IV, indicating a positive effect of unhesitatingly increasing the dose. Earlier studies have not found a clear relation between centre mean insulin dose and HbA1c \(^{7,26}\). We do not know if there was any correlation in Studies III and IV between insulin dose and frequency of hypoglycaemia as we did not have the relevant data.

In Study III, numbers of attendances per patient per year was one of the strongest predictors of high HbA1c level. A causal link is debatable, as patients with increasing HbA1c are likely to attend the out-patient clinic more frequently.

Patient education is essential in diabetes care and is an integral part of the process. Small differences in the content of the message delivered from healthcare professionals and the way it is expressed can affect the recipients’ (the children, adolescents and their parents) understanding. In Study III, members of diabetes care teams with low centre mean HbA1c gave a clear and distinct message about treatment target values, which is consistent with earlier studies \(^{39,146,147}\), but the message was also clearer with regard to diet, the importance of physical activity, structured everyday life, and high frequency of glucose self-monitoring. Language characteristics also revealed a high level of commitment in team members of the Low and Decrease groups. It has been found that 19% of the young adults feel that their physician/diabetes care team do not understand their daily challenges \(^{97}\).

The collaborative process within the team is important to its performance \(^{143}\). Factors associated with success, in terms of centre mean HbA1c, were, as perceived by team
members, a cohesive team with members giving the same message. This is consistent with the findings of others, and suggests that education and professional development should aim to facilitate this collaborative process within the team. Research has demonstrated that properly designed team training programmes can improve team performance, but success is highly dependent on organizational factors such as leadership support and the learning environment.

Our own clinical experience tells us that there is a lack of modern teaching aids and we therefore wanted to use the potential of the Internet in patient education. The web portal, Diabit, that was developed for, and used in the intervention (Study V), was intended as a complement to traditional patient education tools. Diabetes information is available on other web sites, but we could not find any that had been developed with the involvement of users. As both patients and practitioners took part in the development of our portal, it can be regarded as a bottom-up-project. It was a non-commercial, multidisciplinary project and achieved by a collaborative effort. In a qualitative study we found that patients were satisfied with the portal and that they found the information it contained useful. In Study V, we found that Diabit was used both by patients and parents. The interactive and communication features proved popular, especially the social networking pages. Although the most active users had better metabolic control, even those with poor metabolic control were found among the users. In this thesis, Diabit was also evaluated for outcome variables in diabetes care and these are discussed below.

**Outcomes of care**

**Metabolic control**

In Sweden, children and adolescents with diabetes are intensively treated with multiple injections or CSII. However, only 35% of the population in Study III had an HbA1c below the target value at the time of data collection. This increases the risk of late complications affecting a large number of these children and adolescents in later life. Mean HbA1c in the population (DCCT-corrected value 8.3%) was comparable to the levels (DCCT-values) found in two international multicentre studies, i.e. 8.3% and 8.2%, and lower than a Scottish study with 9.1% and a French study with 8.97%. A German study produced a lower mean level of 7.8%, and a mean level of 8.18% was found in a North American population.
Both patient-related (gender, age, duration) and treatment-related (insulin dose) factors affected metabolic control, as shown in other studies \(^7\), \(^23\), \(^28\), \(^40\). The deterioration of HbA1c levels during adolescence indicates that both physical and psychological factors affect metabolic control. The association between poorer metabolic control and longer duration is likely, to some extent, to be due to progressive loss of beta-cell function. The poorer control seen in adolescent girls suggests that more support is needed in this particular group. A main finding in Study III was the difference in mean HbA1c between centres. This could not be explained by differences in characteristics in the populations. In Study IV some reasons were found in the process of care, as described above.

**Health-related quality of life**

The studies that earlier have been carried out on HRQOL in children and adolescents with diabetes have not shown consistent results, and the reasons for this are not clear. In the large Swedish population that was studied in Study II, the findings were similar to those of others who found a higher HRQOL in boys than in girls \(^72\), \(^73\), \(^121\), \(^124\) – again suggesting that girls need extra support and understanding. The reason why HRQOL is higher in those with good metabolic control \(^74\)–\(^76\) than in those with poor metabolic control is not obvious but, in any event, those with poor metabolic control will still need to be given special attention. The family situation must also be taken into account, as perceived HRQOL was higher when parents were living together than when they were separated. The provision of better understanding and support requires an awareness of the child’s social situation.

The scores for generic HRQOL in children and adolescents in the present study are comparable to those found in another Swedish population \(^73\), but parents in Study II rated the generic HRQOL of their child higher. Age and gender differences have also been found in healthy children and adolescents. It has been shown in a large representative sample of European children and adolescents in 12 European countries that children generally have higher HRQOL values than adolescents, and that female adolescents often score lower than their male counterparts. Differences in HRQOL between countries point to the importance of national contexts for the health and wellbeing of children and adolescents \(^150\).

In Study II, groups with lower perceived HRQOL could be identified by using the Disabkids questionnaire. In routine clinical care, this type of questionnaire can be used on an individual level as a starting point for a discussion with the patient. On a population level, it gives useful information about quality of care over time and between groups.
Patients’ perception of quality of care
Patient and parent perceptions of quality of care were the focus of Study I. As found in other studies, the average level of quality of care was high \(^{49,151}\). The areas where low ratings for perceived reality combined with high ratings for importance were found to be information, access to care, and waiting-time. The intervention with the web portal Diabit (Study V) aimed to address some of these areas. The use of the Internet in patient education has the potential to meet some of the need for support during adolescence, as a high proportion of adolescents are Internet users \(^{152}\). In Study V, no effect on quality of care as regards information was found following the intervention. Patients’ and parents’ perception of the need for better information about self-care in Study I is consistent with the practitioners’ view of patient education in diabetes management \(^{60,64,90}\) and highlights that education is a key issue. Interestingly, information about late complications was one information item that received lower reality ratings combined with high importance. This is valuable information for diabetes care teams, as it implies that candid information should be given about the risk of complications.

Effects of the web portal intervention
We could not find any measureable beneficial effects on quality of care as regards information, HRQOL, empowerment, or metabolic control. Nor could we find any adverse effects on these variables. The portal aimed to increase patients’ empowerment, including autonomy. A risk of less favourable outcomes has been found in earlier studies aiming to increase patients’ empowerment and autonomy, e.g. on metabolic control, especially when there was a low level of parental involvement \(^{132,153}\).

Methodological issues
The strengths of Studies I-III and V are the large unselected populations, which may increase the precision of the study. In Study IV, the number of teams in each group is small, reducing the chance of finding significant differences by quantitative analysis. Study III used data from the Swedish paediatric diabetes quality registry, SWEDIABKIDS \(^{79}\). The completeness of information obtained from the register was 100% for gender and age, 93% for duration and age at onset, 90% for HbA1c, 89% for weight, 84% for length, 83% for BMI, 81% for BMI SD, 79% for insulin dose, 76% for injections per day, and 65% for...
Discussion

The QPP questionnaire used to measure patients’ perception of quality of care is based on a grounded theory model and has been validated in an adult population but not in children. We modified the questionnaire on pediatric diabetes care according to best clinical practice. The Disabkids questionnaire used to measure HRQOL was developed in a European project that included interviews and focus groups with children and adolescents. It has been validated in children with a variety of chronic conditions, including diabetes and has been found to be applicable to the Swedish pediatric population. The EQ-5D questionnaire has been proven to be reliable and valid in adults. Some studies have used it to measure HRQOL in children with chronic conditions. In Study III, EQ-5D correlated with disease severity and frequency of problems. These correlations were also found with the Disabkids generic HRQOL and diabetes specific HRQOL, confirming the usefulness of EQ-5D in children. A child version of the EQ-5D has recently been developed. The SWE-DES-SF-10 questionnaire used in Study V to investigate empowerment has not been validated for children or adolescents but has been used in other studies of adolescents. To reduce the risk of low validity, the present studies used the QPP, EQ-5D and SWE-DES-SF-10 questionnaires only in parents as proxies and in adolescents, and not in younger children.

The response rates ranged from 59% to 72% in the surveys in Studies I, II and V. In Study IV the response rate of the e-mailed questionnaire to diabetes team members was 85%. No gold standard for an acceptable response rate exists. When the response rate to mailed physician questionnaires was studied, the average was 61% and remained fairly constant over time. There is a risk of bias if the characteristics of the non-responders differ from the responders, which affects generalizability. In Study I, mean HbA1c and mean age were higher in non-responders than in responders but this is not thought to affect the conclusions drawn.

In Study V, the randomization of patients into intervention and control groups prevented selection bias. The baseline characteristics of the two groups were comparable, reducing confounding factors. Significant differences in outcome variables could not be found between the intervention group and the control group in Study V. This could be due to an inadequate
number of active users in the intervention group. As diabetes team members were blinded and did not know which patients had access to the portal, they could not promote its use. To increase the chance of revealing the effects of intervention, active users were compared with less active users. The obligatory password probably discouraged access and reduced the number of users 149. A more structured intervention programme could possibly increase the use of the portal, enabling differences to be demonstrated.

A generally high level of quality of care was found in Study I. It has previously been found that satisfaction and dissatisfaction can be expressed simultaneously, and patients can be satisfied with one aspect or attribute of care but still express a number of criticisms or reservations about it 157. It has been argued that patient dissatisfaction should be an actively measured outcome of care 151. The QPP questionnaire addresses both the perceived reality and the importance of an issue 48. This construction makes it possible to use the QPP questionnaire to identify areas with which patients and parents are less satisfied. It addresses both the perceived reality and the importance of an issue 48, and the results become interesting when a discrepancy between perceived reality and importance is found. In Study I it was possible to identify areas in need of improvement by using the QPP questionnaire.

Qualitative content analysis is a method of analysing text data, and it is used to infer meaning from content. It has been defined as “the subjective interpretation of the context of text data through the systematic classification process of coding and identifying themes or patterns” 142. In Study IV, summative content analysis was used, beginning with the identification and quantification of words or content in the text. This was followed by latent analysis to discover the underlying meaning of the content. This provides insight into how words and language are actually used. To improve credibility, written answers from respondents were reviewed by two researchers and discussed until consensus was reached. Failure to grasp broader meanings in the text may be a limitation of this method 142. The authors who carried out the analysis were experienced in qualitative research and diabetes clinical care respectively, which also improved credibility 158.
CONCLUSIONS

- The quality of diabetes care for children and adolescents in Sweden is not sufficiently good and needs to improve further if complications in later life are to be avoided. Diabetes care teams must work continuously to improve quality.

- Quality of care can only be properly assessed if the perceptions of children and adolescents, and those of their parents, are taken into account. This information is necessary to identify areas that need improvement and those groups that need extra support. Psychosocial support for children and adolescents with diabetes should be appropriate for age and gender.

- The attitudes of diabetes team members and the message they give patients and parents seem to influence metabolic control in children and adolescents. Team members need to be more aware of how their attitudes affect patients and parents. A clear and consistent message from a unified team appears to have beneficial effects on metabolic control.

- A web portal that includes comprehensive information about diabetes, and the opportunity to communicate with other people with diabetes and with healthcare professionals may be a useful complement to traditional patient education tools. Members of the diabetes team should encourage its use.
FUTURE PERSPECTIVES

- Study IV examined the structure, process, policy, and message to patients and parents as perceived by diabetes team members. The perceptions of patients and parents of the same processes, policies and messages conveyed were also surveyed. These results remain to be analysed. How do children and adolescents perceive the message? Do patients perceive messages in the way the professional intended?

- Further studies of the web portal are planned. The use of the message board and blog will be analysed. The focus will be on active users. School nurses have their own pages on the web portal. Results of a questionnaire about their perception of the supportive role of the portal remain to be analysed.

- Supportive interventions are needed in diabetes care, and their effects must be studied.

- Patient education methods must be continuously developed, and interventions are needed to improve knowledge and empowerment in children, adolescents, and parents. Controlled interventions should be made for certain groups such as adolescent girls and children and adolescents with poor metabolic control. Further research on electronic communication for young people with long-term health problems would also be of value.
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