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Self-management of diabetes in adolescents using insulin pumps

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Abstract

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Insulin pump treatment (CSII) is considered the most physiological way to imitate the healthy body's insulin profile in adolescents with diabetes. However, despite the use of CSII, achieving the recommended disease control is difficult for adolescents.

The aim of this thesis was to explore aspects of self-management of diabetes in adolescents using insulin pumps in order to describe conditions contributing to the recommended disease control.

Three methods of bolusing (normal, dual-wave and square-wave) in connection with pasta meals were tested in a crossover study among 15 adolescents with diabetes to assess whether one method was superior in managing glucose levels. A cross-sectional study among 90 adolescents being treated with CSII was conducted to investigate the management of CSII, including the administration of bolus doses. Two qualitative interview studies, based on the grounded theory method, were performed to gain insight into the processes involved in taking bolus doses and to investigate reasons for missed bolus doses and strategies for avoiding missing them. Twelve adolescents, four parents and one diabetes specialist nurse were interviewed.

No method of bolusing was found to be superior in managing the glucose levels after these meals. The post-prandial glucose peaks were <10 mmol/L, in 48% of the cases, regardless of bolus methods. This indicates that adolescents can be encouraged to individually test which bolus method gives them the most normal post-prandial glucose levels.

The cross-sectional study showed that adolescents were satisfied with CSII, but that 38% had missed more than 15% of the bolus doses the day under study. The frequency of bolus doses correlated with the disease control.

Findings from the interview study revealed the need to clarify the responsibility for diabetes self-management in continuous negotiation between adolescents and parents to avoid insulin omission. The main reason for missed boluses was lost focus, and the strategies for remembering them were agreements involving reminders.

The thesis describes that individual dose testing, clarification of responsibility and agreements involving reminders are conditions contributing to the recommended disease control. The thesis also describes that lost focus and a lack of responsibility can lead to insulin omission and be a hindrance to achieving disease control.

Keywords: Type 1 diabetes, Insulin infusion systems, Insulin omission, Adolescents, Adolescent parenting, Nursing, Qualitative research, Interviews

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*In memory of Anna Kernell, who
posed the questions, but left us too
early.*

List of Papers

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

- I Lindholm Olinder, A., Runefors, J., Smide, B. & Kernell, A. (2009) Post-prandial glucose levels following three methods of insulin bolusing. A study in adolescent girls and in comparison with girls without diabetes. *Practical Diabetes International*, 26(3):110-115.
- II Olinder, A.L., Kernell, A. & Smide, B. (2009) Missed bolus doses: devastating for metabolic control in CSII-treated adolescents with type 1 diabetes. *Pediatric Diabetes*, 10: 142-148.
- III Lindholm Olinder, A., Ternulf Nyhlin, K. & Smide, B. Clarifying responsibility for self-management in adolescents with diabetes using insulin pumps – a qualitative study. Submitted
- IV Lindholm Olinder, A., Ternulf Nyhlin, K. & Smide, B. Reasons for missed meal-time insulin boluses, from the perspective of adolescents using insulin pumps – “lost focus”. Submitted

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Abbreviations

AUC	Area Under the Curve
BMI	Body Mass Index
BMI SDS	Body Mass Index Standard Deviation Score
CGM	Continuous Glucose Measuring
CSII	Continuous Subcutaneous Insulin Infusion
DCCT	Diabetes Control and Complication Trial
E%	Energy %
HbA1c	Glycosylated Haemoglobin A1c
HRQL	Health-Related Quality of Life
ISPAD	International Society for Paediatric and Adolescent Diabetes
MDI	Multiple Daily Injections
NS	Non-Significant
RCT	Randomized Controlled Trial
SMBG	Self-Monitoring of Blood Glucose
QoL	Quality of Life

Abbreviations used in the thesis.

Preface

My interest in diabetes began already in my teen years. One of my friends had diabetes and I had the chance to share her daily efforts to manage living with diabetes. She had to integrate diabetes into her daily life as well as be a teenager.

My obvious professional choice was to become a paediatric nurse and in the late nineties I qualified as a paediatric diabetes specialist nurse. My first area of responsibility was to teach children and adolescents starting with insulin pump treatment. In those days, insulin pumps had just begun to be subsidized and were thus free of charge to patients. Only a handful of adolescents had used insulin pumps in the past, but interest in them was now growing.

During my first year as a diabetes nurse I taught twelve adolescents, three children and their parents about treatment with insulin pumps. The young pump users were followed in a prospective study for two years. The results of this study showed that almost all the participants were very satisfied with the treatment and wanted to keep their pumps. Their disease control improved, although very few had achieved the recommended glucose values. After some time, many adolescents increased their blood glucose levels.

After a few years new technological possibilities became available in the insulin pumps. The question then arose as to whether the possibility to give mealtime bolus doses using different methods was something that could improve disease control. While downloading adolescents' pump history, I became aware of that many of them did not take all their mealtime bolus doses. This could be an explanation for the unsatisfactory disease control. Adolescents with diabetes face a demanding situation in managing their daily life. Diabetes self-management can be seen as a process involving various daily activities. My experiences from having discussions about both obstacles and successes in relation to managing daily life with insulin pumps increased my interest in delving more deeply into this problem area.

Introduction

The worldwide incidence of type 1 diabetes is increasing among children and adolescents (Soltész et al. 2007). In Europe, the prevalence in persons younger than 15 years is expected to have risen by 70% by the year 2020 (Patterson et al. 2009), and in Sweden today approximately 8 000 children and adolescents are diagnosed with diabetes. They attend special paediatric diabetes clinics, where they meet regularly with diabetes care teams, until they reach the age of 18-20 years (SWEDIABKIDS 2009).

Adolescents sometimes experience diabetes as demanding. Diabetes care teams have a great responsibility to support and guide these adolescents and their families in managing the disease. Diabetes specialist nurses collaborating with young people with type 1 diabetes, need to have an understanding of the influence of diabetes when the adolescents want to take risks which may involve their diabetes care (Sjöblad 2008, Pihoker et al. 2009, Court et al. 2009).

The recommended insulin treatment for achieving disease control in adolescents with type 1 diabetes is a basal-bolus regime. This regime consists of either multiple daily insulin injections (MDI) or therapy with an insulin pump (CSII) (Sjöblad 2008, Bangstad et al. 2009).

Insulin pump treatment is at present considered the most physiological way to imitate the healthy body's insulin profile (Bangstad et al. 2009). Despite receiving insulin pump treatment, however, adolescents have difficulty achieving the recommended disease control (de Beaufort et al. 2007, Danne et al. 2008, SWEDIABKIDS 2009). This thesis focuses on self-management in adolescents using insulin pumps.

Background

History of diabetes self-management

A person stricken with diabetes before the discovery of insulin in 1921 did not survive. The total insulin deficit created by type 1 diabetes makes survival without insulin replacement impossible. One way to prolong life for these patients was through a very strict starvation diet. In the long run, however, survival was impossible (Anthony 2002, Allen 2003, www.joslin.org 2010).

After the discovery of insulin in 1921, survival became possible through several daily insulin injections. The patient had to learn how to inject the prescribed amount of insulin dosage. The belief was that patients did as they were told, and there were no discussions regarding self-management activities besides taking these injections. The medical paradigm reigned. However, there were exceptions: the American physician Elliot Joslin in Boston was a pioneer in involving diabetic patients in their treatment already before the discovery of insulin. He arranged specific education for the patients he treated. The Joslin Diabetes Centre was one of the first to use nurses as diabetes educators. Their tasks were to teach patients and families how to inject insulin, test urine for glucose and interpret the results. They also taught patients how to compute food values and treat insulin reactions, in order to help them to manage their treatment at home (Anthony 2002, Schilling et al. 2002, Allen 2003, www.joslin.org 2010).

Long-acting insulin became available in the 1930s, and most patients with diabetes received one or two injections per day. For many years there was a debate between different diabetes clinics about the need for blood glucose control. Some stressed the necessity to have as normal blood glucose values as possible, with the insulin dosage based on the levels of glucosuria. These patients also had to follow dietary restrictions. At other diabetes clinics, the insulin dosage was based on the avoidance of ketoacidosis and symptoms of both hyper- and hypoglycaemia. These patients ate a regular diet (Allen 2003, Anthony 2002, www.joslin.org 2010).

In the early 1980s it became possible for patients to monitor their blood glucose at home. Previously, the levels of glucose in the urine had been a

crude measurement of the levels of glucose in the blood. The ability for patients to self-monitor blood glucose, together with knowledge about how to interpret the results, made it possible to more actively keep blood glucose values closer to the normal range (Anthony 2002).

During the early 1980s it also became possible to measure glycaemic control over a long period of time by looking at the glycosylated haemoglobin A1c (HbA1c). HbA1c refers to a minor haemoglobin component formed by the adduction of glucose to haemoglobin. The use of HbA1c to measure glycaemic control in diabetic patients was proposed in 1976 by Anthony Cerami and colleagues. The authors found that the HbA1c concentration reflected the mean glucose concentration over the previous two to three months, and claimed that examining HbA1c levels was a useful way to measure glucose control in diabetic patients (Koenig et al. 1976).

The possibility to self-monitor blood glucose and to measure glycaemic control over a long period of time by looking at HbA1c levels made it possible to investigate the necessity of strict blood glucose control (Anthony 2002).

In 1982 in Stockholm, the Stockholm Diabetes Intervention Study was initiated. In this study, 102 patients were randomized to intensive or standard diabetes treatment. Intensive treatment consisted of at least three injections per day, individual education and frequent contact with a physician, initially every second week. Standard treatment consisted of two injections per day and visiting a physician every fourth month. The results showed that intensive treatment, resulting in lower blood glucose levels, slowed the development of micro-vascular diabetes complications like kidney damage and impaired vision (Reichard et al. 1993).

Another study was the Diabetes Control and Complication Trial (the DCCT study). This study included 1 441 patients aged 13-39 years. The patients were randomly assigned, to either intensive or conventional therapy. The intensive therapy consisted of three or more daily insulin injections or insulin pump therapy, and at least four instances of self-monitoring of blood glucose (SMBG) per day. It also included contact with the diabetes care team at least once a month. The goal was to keep the blood glucose at as normal a level as possible. The conventional therapy consisted of one or two daily insulin injections, daily SMBG and urine glucose control. The goals in the latter group were absence of symptoms of glucosuria or hyperglycaemia and absence of ketonuria. The differences in late complications were significant between the two groups. The results confirmed that intensive insulin treatment with the goal of keeping the blood glucose as close to normal as possible should be recommended, to avoid late disastrous micro-vascular diabetes complications (DCCT 1993, DCCT 1994).

The possibility to perform SMBG and measure long-term glycaemic control with HbA1c as well as the results from the DCCT study and other stud-

ies contributed to a gradual shift from medical management to self-management of diabetes. In Sweden a Public Health Act was implemented during this time, stipulating that patients had the right to be involved in their own care and treatment (SFS 1982). Some doctoral theses written by Swedish nurses with a patient-centred perspective contributed to this shift in diabetes management (Ternulf Nyhlin 1990, Lundman 1990, Wikblad 1991). The self-management was conducted in collaboration with diabetes care teams, including diabetes specialist nurses. The patients became more actively involved in their own care, and improved their ability to manage the disease themselves (Anthony 2002, Schilling et al. 2002).

Besides the possibility to perform SMBG and measure long-term glycaemic control, a new tool for treatment became available in the early 1980s: the insulin pump. In insulin pump treatment, insulin is infused subcutaneously by a pocket-sized pump. The first reported trial of insulin pumps in paediatric diabetes care was published in 1979. Seven adolescents received two to four days' treatment with insulin pumps, and their blood glucose levels and fluctuations in blood glucose were lower with this method than with injections (Tamborlane et al. 1979). Still, interest in using an insulin pump was low before the results from the DCCT study were published. However, when the evidence supporting intensive therapy was clear, interest in using the pump began to grow. In Sweden, the cost of insulin pumps and accessories began being subsidized in 1997 (Hanas 2002). Since then, the use of insulin pumps in Sweden has increased (SWEDIABKIDS 2009).

Adolescence

Adolescence can be seen as a transition between two stable states, that of being a child to that of being an adult. A transition phase can be described as a period of instability in which the individual has to learn new tasks, behaviours and self-perceptions (Lenz 2001).

During adolescence, young individuals should develop autonomy and leave their parents. Relationships with peers and new friends become important during this phase in life. One task is to begin to take care of one's health oneself (Lenz 2001).

Youths with diabetes have to gradually take over the responsibility for the treatment of diabetes from their parents during adolescence (Schilling et al. 2006). Viklund (2008) highlighted factors which could facilitate or aggravate the transition for adolescents with diabetes. She mentioned good knowledge about diabetes, self-care and glycaemic control as factors leading to a successful transition. Furthermore, she suggested an interest in new treatment, a good social network, low vulnerability, high self-esteem, a high level

of independence and low impact of diabetes as contributing factors to a successful transition, resulting in good physical and psychological well-being.

Adolescence is a period of rapid physical, psychological and social developmental changes. Physical development, including puberty, is determined by an individual's biological clock. The age at which puberty starts and how long it lasts vary depending on the individual. Psychological and social development is dependent on environmental and cultural influences (Christie and Viner 2005). Both physical and social development seems to start at an earlier age now than some decades ago; youths 9-12 years old have the same interests and lifestyles today as teenagers had 10-15 years ago (Lindblad and Lindgren 2010).

Self-management of diabetes in adolescents

Adolescents with diabetes have to perform different daily activities in order to feel well despite having diabetes. Many adolescents are able to handle the diabetes so that it is manageable within the context of an adolescent's life. They perceive the diabetes management as a habit. On the other hand, some adolescents may perceive their diabetes as a nightmare and feel tethered to a never-ending disease (Kyngas and Barlow 1995, Dickinson and O'Reilly 2004).

In daily life with diabetes, the need to be able to manage by oneself is paramount. In collaboration with diabetes care teams who initiate medical treatment and guide the patient in achieving profound diabetes knowledge, the ultimate outcome of diabetes management shall be reached (Wikblad 1991, Silverstein et al. 2005, Swift 2009).

In the literature, the concept of diabetes self-management has no uniform terminology. Various authors have used concepts such as self-care, diabetes self-care responsibility, self-care autonomy and self-care management (Schilling et al. 2002).

In this thesis I have chosen to use the term *self-management* to describe all the activities adolescents and their parents perform in order to manage the diabetes. This choice is strengthened by the definition suggested by Schilling et al. (2002). They evaluated the concept of self-management of diabetes in children and adolescents, highlighting the complexity of the concept and stating the many dimensions involved. Their evaluation is based on 99 articles on the self-management of diabetes in children and adolescents. The authors reviewed the articles and suggested the following definition (Schilling et al. 2002, p. 92):

“Self-managing of diabetes in children and adolescents is an active, daily, and flexible process in which youth and their parents share responsibility and decision-making for achieving disease control, health and well-being through a wide range of illness-related activities”.

The above definition consists of the goals of self-management, disease control, health and well-being. It states that self-management is a process which is active, daily and flexible; responsibility for the process is shared with the parents. The definition also states that the process includes a wide range of activities. Both individual and external variables have been shown to have a relationship with self-management. Age, sex, motivation, maturity and skills are examples of individual variables that can influence self-management. External variables such as support from the family and the parent-child relationship are also important for self-management. The social network surrounding the adolescent and the parents, with support from friends and the diabetes care team, can also contribute to the adolescent's self-management (Schilling et al. 2002).

Self-management goals

The goals of self-management are to achieve disease control, health and well-being (Schilling et al. 2002). The International Society for Paediatric and Adolescent Diabetes (ISPAD) international guidelines also highlight the importance of achieving these goals (Rewers et al. 2009, Pihoker et al. 2009, Delamater 2009).

The recommended disease control is to keep the blood glucose levels as close as possible to normal values to prevent both acute and late diabetes complications (Reichard et al. 1993, DCCT 1993, DCCT 1994). Disease control is measured by examining the HbA1c. ISPAD guidelines recommend an HbA1c target of < 7.5%; this is expressed in DCCT values, while the Mono-S value used in Sweden is ~ 6.5 – thus the Swedish guidelines recommend an HbA1c value of < 6.5%. The HbA1c value should be measured every third month (Sjöblad 2008, Rewers et al. 2009).

Unfortunately, many adolescents do not achieve the recommended levels of disease control (de Beaufort et al. 2007, Hanberger et al. 2008, SWEDIABKIDS 2009). This unsatisfactory disease control most probably has both physiological and psychological reasons (Rewers et al. 2009, Court et al. 2009). During the adolescence period, different hormones can decrease insulin sensitivity. Adolescents with diabetes have hyper-secretion of GH (Growth hormone) and low levels of IGF-1 (Insulin-like Growth Factor I), which contribute to increased insulin resistance and make it more difficult to determine the insulin dosage (Ekstrom et al. 2007, Sjöblad 2008). In adolescent girls, glucose levels may depend on where they are in their menstrual cycle (Moberg et al. 1995).

Sometimes the adolescent's own goal for the self-management is not in congruence with the recommended goals. In a not yet published study from London, it was shown that adolescents with high HbA1c values chose to have blood glucose levels which were low enough to prevent ketoacidosis.

These glucose levels did not give the adolescents any symptoms of either high or low blood glucose levels; they had *perfect poor control*. They felt healthy for the moment; however, these high values increased the risk of late complications (Sjöblad 2008, p. 157). Keeping one's diabetes as invisible as possible can be another goal, which can conflict with both the insulin treatment and the frequent monitoring of blood glucose (Schilling et al. 2002).

Self-management process

The self-management process is a lifelong, active and proactive daily process which includes everyday planning and activities to prevent future complications related to diabetes. The process has to be flexible. For example, the same insulin regimen does not work every day, as days with a great deal of exercise or illness require insulin adjustment. Adolescents have to consider whether they have gotten enough insulin and remember to bring along their blood glucose monitor apparatus. Furthermore, they have to plan where and what they can eat, whether they need to bring something extra to eat, and so on.

Moreover, the process involves shifting and shared responsibility and decision-making between the parents and the adolescent. Depending on the adolescents' age and maturity level, he/she can assume different levels of responsibility. Viklund and Wikblad (2009) studied factors affecting decision-making competence among adolescents and identified cognitive maturity, personal qualities, earlier experiences, social network and parental involvement as important factors in decision-making. The authors concluded that the adolescents' immature decision-making competence should be respected.

The self-management process involves collaboration with the diabetes care team at the paediatric clinics. The team have to provide education and support to the adolescents and their families regarding how to manage the disease in all daily situations (Sjöblad 2008, Pihoker et al. 2009). Adolescents perceive this collaboration as positive if the members of the diabetes care team can talk directly to them in a motivational manner, are interested in their daily life and involve the whole person instead of just the disease (Dickinson and O'Reilly 2004, Karlsson et al. 2008).

Self-management activities

The treatment of diabetes requires many complex self-management activities. It consists of either multiple daily insulin injections (MDI) or treatment with an insulin pump (continuous subcutaneous insulin infusion, CSII). An insulin bolus dose is needed with every meal and snack. Adolescents using MDI inject the dose with an insulin pen or a syringe. Those using CSII press

a button on the insulin pump and choose the appropriate dose. Injecting the appropriate insulin dose requires skill; the intake of carbohydrates, the actual blood glucose level, physical activity, infection and stress are examples of variables that must be considered before the injection (Sjöblad 2008, Bangstad et al. 2009).

Studies have shown that insulin omission is rather common among CSII-treated adolescents (Burdick et al. 2004, Pankowska et al. 2005, Vanderwel et al. 2010), and it is probably common among MDI-treated adolescents too, but more difficult to detect.

Burdick et al. (2004) studied 48 CSII-treated children and adolescents aged 7-20 years. He reported that 65% had missed at least one mealtime bolus dose per week; missed boluses with snacks were not included. Pankowska et al. (2005) studied 100 CSII-treated children and adolescents aged 1.6-18 years, and found that 10% had missed mealtime bolus doses. It was mainly adolescents with a long duration of diabetes who missed the doses. In this study, a missed mealtime bolus dose was defined as fewer than two bolus doses per day. In both studies, the frequency of missed bolus doses correlated with the HbA1c values. Vanderwel et al. (2010) studied insulin omission in connection with afternoon snacks, and report that this is common among adolescents and results in high glucose excursions.

In the 2004 study by Burdick et al., the most frequently reported reason for missing boluses was “forgetting”, which was reported by 67% of the participants. Other reasons were a fear of hypoglycaemia (6%), inconvenience of the pump location (2%) and being too busy (8%).

Another reason for omitted bolus doses can be to control weight. The wish to be thinner is reported to be common among adolescents. In a study among 197 healthy adolescents, 47% reported that they wanted to be thinner and 25% had tried to lose weight (Edlund et al. 1994). Neumark-Sztainer et al. (2002) studied 70 girls and 73 boys aged 12-21 years with diabetes, and among the girls 10% reported skipping insulin doses to control their weight while only one of the boys reported this behaviour. Takii et al. (2008) studied 109 adult females with diabetes and clinical eating disorders. The duration of insulin omission was the factor most associated with late diabetes complications such as retinopathy and nephropathy. The authors concluded that it is important to identify those who have diabetes and eating disorders with insulin omission to be able to give appropriate help. Swenne (2001) has shown that, prior to the onset of eating disorders, healthy adolescent girls were heavier than their peers and had a BMI over the normal range. Being heavier than one's peers can influence one's body image and lead to a decision to diet, which in turn may lead to the development of eating disorders in predisposed adolescents.

Another self-management activity adolescents with diabetes are expected to perform is the self-monitoring of blood glucose (SMBG), which has to be conducted frequently; a minimum of four monitoring occasions per day is recommended. The self-monitoring is done to be able to evaluate and determine the insulin dosage and to prevent acute and late complications. Difficulty injecting the appropriate amount of insulin, but also insufficient self-management, may lead to blood glucose values above or below normal values. These high or low blood glucose values can lead to unpleasant symptoms (Sjöblad 2008, Rewers et al. 2009).

A high blood glucose value leads to increased thirst, polyuria and tiredness. A deficit of insulin leads to stomach pain and vomiting and, if not diagnosed in time, ketoacidosis. Ketoacidosis is an acute complication of diabetes and can lead to unconsciousness and even death if it is not properly treated (Sjöblad 2008, Wolfsdorf et al. 2009). Long-standing hyperglycaemia leads to a higher risk for late diabetes complications (Reichard et al. 1993, DCCT 1993, DCCT 1994).

A blood glucose level below the normal value leads to different unpleasant symptoms of hypoglycaemia. These can include irritability, shaking, sweating and headache, and sometimes more severe symptoms like unconsciousness and seizures. Hypoglycaemia must be treated through the intake of fast-acting carbohydrates, i.e. glucose tablets. Severe hypoglycaemia involving unconsciousness or seizures requires treatment with glucagon or glucose injection (Sjöblad 2008, Clarke et al. 2009).

Difficulty keeping one's blood glucose within the normal range can be seen as walking a fine line, which is described by Ternulf Nyhlin (1990).

Adolescents using an insulin pump have to deal with other special practical self-management activities, which require special education. These activities include filling cartridges and infusion sets with insulin and replacing infusion sets and needles (Hanås 2004, Rodgers 2008).

Diabetes disease control

The recommended disease control is, as mentioned, as normal as possible blood glucose levels. This requires adequate self-management, with appropriate doses of insulin, evaluated through frequent SMBG.

The recommended insulin treatment for achieving disease control in adolescents with type 1 diabetes is a basal-bolus regime. This regime consists of either multiple daily insulin injections (MDI) or therapy with an insulin pump (CSII) (Sjöblad 2008, Bangstad et al. 2009).

Insulin pump treatment

Insulin pump treatment is presently considered the most physiological way to imitate the healthy body's insulin profile (Bangstad et al. 2009). When an insulin pump is used, a pre-programmed basal dose is continuously infused. The basal dose consists of about half the amount of the total daily insulin dose. The other half of the dose is delivered in so-called bolus doses, which are taken with every meal or snack. They provide an extra dose of insulin in order to reduce the increased blood glucose level which follows after food intake. The bolus doses are added manually by pressing a button on the pump, which releases a defined insulin dose (Sjöblad 2008, Rodgers 2008, Bangstad et al. 2009).

Today, CSII is in use in all paediatric ages, from infants to teenagers (Olinder et al. 2006, Danne et al. 2006, Pankowska et al. 2009, SWEDIAB-KIDS 2009, Bangstad et al. 2009). Recent years have seen an increase in the introduction of CSII in adolescents in many countries (Danne et al. 2006, SWEDIABKIDS 2009). In 2008, approximately 29% of Swedish children and adolescents with diabetes used an insulin pump (SWEDIABKIDS 2009).

Treatment with CSII is more expensive than treatment with MDI. If the treatment results in better disease control with fewer hypoglycaemic events it is probably cost-effective, as it may increase quality of life and decrease the development of late diabetes complications (Scuffham and Carr 2003, Colquitt et al. 2004, Roze et al. 2005, Nuboer and Bruining 2006, St Charles et al. 2009).

Disease control in adolescents using the insulin pump

In a recently published Cochrane review, the effect of CSII treatment is compared with MDI treatment in a review of 23 studies. In these studies, a total of 976 participants have been randomized to treatment with either CSII or MDI. A difference in HbA1c of -0.3%, favouring CSII, is found. Severe hypoglycaemias seem to be reduced with CSII, but there is no difference in non-severe hypoglycaemias. Seven of the studies included participants less than 18 years of age, and in these studies the difference in HbA1c is -0.2%, also favouring CSII (Misso et al. 2010).

Many studies reporting the effect on disease control in adolescents receiving CSII compared with MDI have been published during the past ten years (Weintrob et al. 2003, Cohen et al. 2003, Plotnick et al. 2003, Willi et al. 2003, Doyle et al. 2004, Alemzadeh et al. 2004, Juliusson et al. 2006, Sulli and Shashaj 2006, Hanas and Adolfsson 2006, Wood et al. 2006, Scrimgeour et al. 2007, Lindholm-Olinder et al. 2007, Skogsberg et al. 2008, Nuboer et al. 2008, Johannesen et al. 2008, Jakisch et al. 2008, Muller-Godeffroy et al. 2009). Five of these are randomized controlled studies (RCTs) and the others

are observational cohort-studies, some of which include a control group with MDI.

The RCTs and the observational cohort studies with control groups comparing HbA1c values between MDI and CSII in adolescents are presented and their evidence graded in Table 1. The evidence grading has been done according to the GRADE system to classify the quality of evidence. This system classifies the quality of evidence on one of four levels – high, moderate, low, or very low. Evidence based on RCT begins at high quality of evidence, but the grade may decrease if the quality is low. Observational trials always begin at a low level of evidence, but the level may increase. When a study is evidence graded, its external and internal validity is assessed. Furthermore, the study's precision and statistical power are investigated (Guyatt et al. 2008a, Guyatt et al. 2008b, Guyatt et al. 2008c, Guyatt et al. 2008d, Schunemann et al. 2008).

Five of the seven RCTs included in the Cochrane review comparing treatment between CSII and MDI in participants less than 18 years of age were published during the past ten years, and include only adolescents and children (Weintrob et al. 2003, Cohen et al. 2003, Doyle et al. 2004, Skogsberg et al. 2008, Nuboer et al. 2008) (Table 1). These studies are classified as having moderate evidence. The external validity is low to moderate in all studies; none report the eligible population from which the participants were drawn. Today, all RCTs must present a consort (consolidated standards of reporting trials) flow diagram, which allows the reader to follow the inclusion and exclusion of participants in all steps (Altman et al. 2001, Moher et al. 2001). The internal validity of the studies is also uncertain, as three do not report how the randomization was carried out (Weintrob et al. 2003, Cohen et al. 2003, Skogsberg et al. 2008). It is not applicable to conduct a blinded trial when comparing CSII and MDI, but the outcomes assessor can be blinded. None of the studies report whether this has been done, and only one reports the deliberation and power calculation behind the choice of sample size (Skogsberg et al. 2008). Three of the RCTs had a short follow-up time, and it can be discussed whether this time was long enough to truly explore the treatment effects (Weintrob et al. 2003, Doyle et al. 2004, Nuboer et al. 2008). In one study, all participants were newly diagnosed with diabetes (Skogsberg et al. 2008). Nuboer et al. (2008) have also included younger children and present a very broad age range; this broadness can make it more difficult to evaluate the results. The results of the studies differ: Four did not show any significant differences in disease control between CSII and MDI (Weintrob et al. 2003, Cohen et al. 2003, Skogsberg et al. 2008, Nuboer et al. 2008). Doyle et al. (2004) showed a difference between the groups, with a greater improvement in the CSII group. Including all five studies in a meta-analysis shows a difference between the treatment of -0.27, favouring CSII ($p=0.001$) (*Figure 1*).

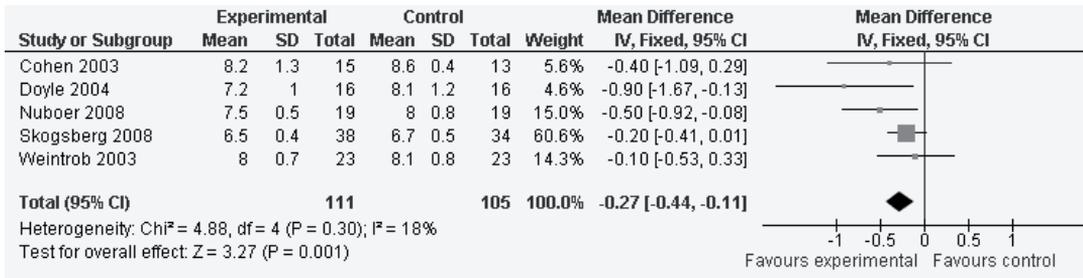


Figure 1. Forest plot showing effect of CSII compared to MDI on HbA1c values in adolescents.

In the observational cohort studies with control groups (Table 1), the participants had chosen CSII treatment and the results were compared with a matched group using MDI during the same period of time. These studies are classified as having low evidence; the fact that the participants had chosen CSII decreases the validity. It is also difficult to consider all important potential confounding factors. In these studies there were no significant differences between the groups; however, in three studies the HbA1c values decreased within the CSII groups (Alemzadeh et al. 2004, Lindholm-Olinder et al. 2007, Johannesen et al. 2008). The sample sizes were perhaps too small to measure between-group differences. None of the studies have reported any power calculations to determine the sample size. One study had a three-year follow-up and during the first year the CSII group had significantly lower HbA1c values than the MDI group (7.5 ± 1.0 vs. 7.7 ± 1.2); however, after three years there was no difference between the groups (Jakisch et al. 2008). Johannesen et al. (2008) did not report the standard deviation values. One study used short-acting human insulin in the pumps (Johannesen et al. 2008), while all the other studies used a more rapid-acting insulin analogue, aspart or lispro.

Among the observational cohort studies without control groups published during the past ten years, all report a decrease in HbA1c after switching to CSII from MDI. This decrease varies between 0.3 and 0.8% units in HbA1c (Plotnick et al. 2003, Willi et al. 2003, Juliusson et al. 2006, Sulli and Shashaj 2006, Wood et al. 2006, Hanas and Adolfsson 2006, Scrimgeour et al. 2007, Muller-Godeffroy et al. 2009). The results of these observational cohort studies can have been affected by different confounding factors, which cannot be controlled for in the same way as in randomized controlled studies. The decrease in HbA1c values seems to be greater with higher baseline values, an effect also reported in studies conducted on adults (Retnakaran et al. 2004).

Table 1. RCTs and observational cohort studies with control groups measuring differences in glycaemic control between treatment with MDI and CSII.

Authors (Publ. year)	Design	Age of participants (years)	Participants (n)	Mean HbA1c (SD) Baseline (%)	Mean HbA1c (SD) End of study (%)	Mean diff in HbA1c:	Duration of study (months)	Evidence Grade
Weintrob et al. (2003)	RCT <i>Crossover</i>	9.4-13.9	CSII: 23 in total MDI: total	8.3±1.1	8.0±0.7	-0.3	3.5	M
Cohen et al. (2003)	RCT <i>Crossover</i>	14-18	CSII: 15 MDI: 13	8.3±1.1 8.58±0.82 8.48±1.4	8.1±0.8 8.15±1.3 8.57±0.44	-0.2 -0.43 +0.09	6	M
Doyle et al. (2004)	RCT <i>Parallel</i>	8-21	CSII: 16 MDI: 16	8.1±1.2 8.2±1.2	7.2±1.0 8.1±1.2	-0.9 -0.1	4	M
Skogsberg et al. (2008)	RCT <i>Parallel</i>	7-17	CSII: 38 MDI: 34	8.2±0.4 8.4±0.5	6.5±0.4 6.7±0.5	-1.7 -1.7	24	M
Nuboer et al. (2008)	RCT <i>Parallel</i>	4-16	CSII: 19 MDI: 19	7.66±0.8 7.98±1.07	7.49±0.50 7.97±0.78	-0.17 -0.01	3.5	M
Alemzadeh et al. (2004)	<i>Cohort study with control group</i>	10.1-17.8	CSII: 40 MDI: 40	8.4±1.0 8.5±1.1	7.8±0.8 8.2±0.9	-0.6 -0.3	12	L
Lindholm-Olinder et al. (2007)	<i>Cohort study with control group</i>	7-15	CSII: 12 MDI: 12	8.5±1.5 8.6±1.6	7.5±0.9 8.3±1.5	-1.0 -0.3	24	L
Johannessen et al. (2008)	<i>Cohort study with control group</i>	15.6±1.9 16.2±2.3	CSII: 30 MDI: 26	9.5±1.5 9.7±1.6	8.9 9.5	-0.6 -0.2	12	L
Jakisch et al. (2008)	<i>Cohort study with control group</i>	8-14	CSII: 199 MDI: 309	7.5±1.0 7.5±1.0	8.1±1.6 8.0±1.6	+0.6 +0.5	36	L

RCT= Randomized control study. M=Moderate evidence. L=Low evidence.

Technological possibilities with insulin pumps

Insulin pumps offer certain technological possibilities which as of yet are not available in insulin pens. For example, pumps offer different methods of bolus administration. It is also possible to download the pump data to a computer to be able to examine what actions have been performed with the pump. Another often used feature is to decrease or increase the insulin basal rate for some hours, when the need for insulin is lower or higher than usual. The insulin pump also offers the possibility to set alarms, for example to take bolus doses (Hanås 2004, Rodgers 2008).

Different methods of bolusing

CSII offers different methods for taking bolus doses to avoid post-prandial hyperglycaemia. The normal bolus method is to give the whole insulin dose at once. With an insulin pump, it is possible to give one part as a normal bolus dose and one part as a prolonged bolus dose, referred to as the dual-wave bolus method. It is also possible to give the whole dose over a longer period of time, as is done in the square-wave bolus method (Hanås 2004, Rodgers 2008).

Previous studies have demonstrated that the dual-wave bolus method results in less post-prandial hyperglycaemia after pizza meals containing high levels of carbohydrates, fat and calories (Chase et al. 2002, Lee et al. 2004, Jones et al. 2005). Chase et al. (2002) studied the difference between normal bolus, two normal bolus doses, dual-wave and square-wave bolus in nine adolescents. The adolescents ingested pizza, tiramisu and non-diet cola and their blood glucose levels were followed for six hours. The dual-wave method showed the lowest blood glucose increase. The other two studies were conducted on adults. Both studies compared normal and dual-wave bolus doses given in conjunction with pizza meals, and both found that the dual-wave bolus was the most favourable (Lee et al. 2004, Jones et al. 2005).

Downloading of pump data

Another technological feature of the pump is the possibility to download the pump history to a computer. This makes it possible to identify the history of basal rates, alarms, all bolus doses given, etc. This equipment is often used clinically to evaluate the treatment and investigate how the pump is used, for example to detect whether bolus doses are being taken appropriately. This possibility has been used in studies to investigate the frequency of insulin omission and other pump actions (Burdick et al. 2004, Pankowska et al. 2005, Vanderwel et al. 2010).

Health, well-being, QoL and treatment satisfaction

Every day, adolescents with diabetes have to accept and integrate many activities related to the diabetes disease, activities that other young people in the same age group do not need to bother about. International guidelines highlight the importance of achieving good health despite having diabetes. According to these guidelines, the diabetes care team should also provide care that results in high quality of life (QoL) and treatment satisfaction. The guidelines also recommend regular measurement of QoL (Sjöblad 2008, Pihoker et al. 2009, Delamater 2009).

Health and well-being

The World Health Organization (WHO 1948) defines health “as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. This definition has been used since 1948, but has been criticized as being too utopian (Larson 1999, Snellman and Wikblad 2006). According to this definition it is very hard to achieve health, and a person with a disease, such as an adolescent with diabetes, is always unhealthy.

Adolescents with diabetes often feel healthy although they have to handle the demanding self-management to keep the disease under control. As a matter of fact, many of them also feel healthy when the disease is out of control, having *perfect poor control*, without symptoms of either high or low blood glucose (Sjöblad 2008 p.157).

Two views of health can be identified in different definitions. One is the biological view, in which a person who does not have a disease is healthy. Every person who has a disease is unhealthy; this means that a person with diabetes is always unhealthy. The biological definition of health has been described by Boorse (1977), who claims that it is possible to measure biological functions and determine what is normal and what is abnormal. A person with an abnormal function is unhealthy.

The other view of health is the holistic view, in which the perspective focuses on the whole human being. A holistic theory of health is described by Nordenfelt (1991), who defines health as having the capacity to fulfil and realize all one’s vital goals. A person is unhealthy or only partly unhealthy if he/she does not have the capacity to realize his/her vital goals or can only partly realize them.

In the holistic definition, health can be seen as a continuum between being totally unhealthy and totally healthy. Antonovsky (1991) also claims that health is a continuum, expressing it as a resource of the individual and stating that a person can move along this continuum. He asserts that as long as a person has a breath of life he/she is not totally unhealthy.

Health is a basic concept in nursing and is discussed by nurse theorists. Henderson and Travelbee stress the fact that health is an individual experience, carrying different meanings for different persons, and that every patient must define what health and recovery mean to them (Harmer and Henderson 1955, Travelbee 1971, Kirkevold 1994). This is in line with the definition by Nordenfelt (1991), as the vital goals can differ between individuals.

In this thesis the definition by Nordenfelt (1991) has been used to understand health. Health is also seen as a continuum between being totally unhealthy and totally healthy, which is described by Antonovsky (1991). An adolescent with diabetes may increase his/her health with an adequate self-management and sufficient knowledge.

Inner strength is a human resource which promotes well-being and is connected to health. In an attempt to gain an understanding of inner strength, Lundman et al. (2010) have performed a theoretical analysis of concepts which have been shown to constitute inner strength. Their analysis resulted in an understanding of inner strength based on four dimensions and the interactions between them. The dimensions are connectedness, firmness, flexibility and creativity. Inner strength means to be connected to others – to family and friends, but also to society, nature and spiritual dimensions; to shoulder responsibility for oneself and others. It also means to stand with both feet firmly on the ground and to be creative and flexible. According to Lundman et al. (2010), being aware of the dimensions of inner strength can help health care providers support patients in using their own resources. It can be fruitful to talk about the different dimensions with adolescents, for example discuss how they perceive their connection with their parents and peers. Meeting others with diabetes may increase their creativity and flexibility. Viklund (2008) has described how meeting others at diabetes camps or in group education can increase one's openness to new diabetes treatment.

Well-being and QoL

Quality of life (QoL) has been defined as “an individual's perception of their position in life in context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO 1993 p. 153).

QoL is a combination of objectively and subjectively indicated well-being. It is possible to measure this multidimensional concept with different instruments, and the results describe how well or poor life is at the time of monitoring. Objective well-being can be assessed by measuring, e.g., economic resources, residence and sickness days. Subjective well-being can be assessed by measuring life satisfaction, perceived health and well-being in different domains, e.g. physical, social and emotional well-being. The best way to assess QoL in adolescents is through a combination of objective and subjective measuring (Wallander et al. 2001).

UNICEF (2007) has published an investigation concerning health and well-being among children and adolescents in 21 OECD countries. Three of the objective well-being parameters were ranked highest among the Swedish adolescents, who had the best socioeconomic conditions, the health care and prevention of risk factors. However, perceived health and well-being among Swedish adolescents was not at the top but rather in seventh place. In the dimension concerning relations to peers and parents, the Swedish adolescents were in fifteenth place. Only 50% of them felt that their parents spent time just talking to them. Another finding was that girls (in all countries) reported lower perceived health and well-being than boys did. This latter finding has been described in several studies (UNICEF 2007, Lindblad and Lindgren 2010).

There are several instruments for measuring QoL and perceived health in adolescents. It is recommended to use both a generic and a diabetes-specific instrument to measure QoL and disease impact on perceived health in adolescents with diabetes. It is an advantage if the instrument is used internationally, as this allows for comparison between different countries and settings. Difficulties in translations between countries can be a problem; it is recommended to have at least one forward and one backward translation, as well as cross-culture harmonization of the translation (Bullinger 2006).

Health and QoL among Swedish adolescents with diabetes

Few instruments have been translated to Swedish for youths with diabetes. Two that are available in Swedish are the “Disabkids” instrument and “Check Your Health”. The former has been developed cross-nationally in a group of seven European countries. It measures QoL and disease impact on perceived health in children with different chronic conditions. Disabkids consists of generic and various disease-specific questionnaires (Baars et al. 2005, Bullinger 2006, Simeoni et al. 2007). Check Your Health measures perceived health and QoL, and is easy to use among both adolescents and adults. It is constructed as four vertical thermometer scales and measures physical, social and emotional perceived health and overall quality of life. Check your Health can also be used to measure the impact of diabetes (Wikblad 2003, Viklund and Wikblad 2010).

Both these instruments have recently been used in Sweden (Chaplin et al. 2009, Hanberger et al. 2009, Viklund and Wikblad 2010).

Chaplin et al. (2009) have used Disabkids to assess QoL and disease impact on perceived health among 361 children and adolescents (aged 8-18 years) in western Sweden. They have also compared the data with the Disabkids European field study data. The data sets showed similar results, but it seemed to be easier for the Swedish youths to accept diabetes and treatment. Another small, but significant, difference was that the Swedish youths found it more difficult to have positive social relationships and felt that they were

hindered from doing things with others due to diabetes. As shown in other studies, adolescent girls scored lower on perceived health.

Hanberger et al. (2009) have used Disabkids among 150 adolescents and 95 children from two paediatric clinics in Sweden. Also in this study, the authors found that adolescent girls perceived lower general and diabetes-specific health than adolescent boys did. Another finding was that adolescents with parents who were separated reported lower perceived health than did those with parents who were living together. The study also reported a correlation between HbA1c and diabetes-specific health in adolescents.

A study using Check your Health among 199 adolescents reported that the girls perceived a higher impact of diabetes on QoL and physical health than the boys did. Another finding was that adolescents with better perceived health had lower HbA1c values (Viklund and Wikblad 2010).

Health, well-being and QoL among adolescents using insulin pumps

Health, well-being and QoL have been measured to evaluate the effect of insulin pump treatment in adolescents in a number of studies.

In four of the randomized trials presented in Table 1, diabetes-specific health and QoL were measured. In three of the studies, “Diabetes Quality of Life: Youth” (DQOLY) (Ingersoll and Marrero 1991) was used (Weintrob et al. 2003, Cohen et al. 2003, Doyle et al. 2004), and in one the “Paediatric Quality of Life Inventory” (PedsQL) (Varni et al. 2003) was used (Nuboer et al. 2008). However, no differences were found between the MDI and CSII groups, although perceived quality of life increased in the CSII group in the within-patient comparisons in one study (Nuboer et al. 2008). In an observational cohort study, it was shown that the impact of diabetes measured with the DQOLY decreased with CSII (McMahon et al. 2005). Generic and diabetes-specific QoL were also measured in a German prospective observational study on children and adolescents starting with CSII. The instruments used were KIDSCREEN (generic QoL) and the KINDL-DM (diabetes-specific QoL) (Ravens-Sieberer et al. 2007, de Wit et al. 2007). Generic quality of life did not change after starting with CSII, but the diabetes-specific quality of life increased (Muller-Godeffroy et al. 2009).

As the responsibility for self-management of diabetes in adolescents is shared between the parents and the adolescent (Schilling et al. 2002), beginning with CSII can affect the whole family. A Norwegian study showed that the limitation experienced by families due to adolescents’ general health and well-being, measured using the “Child Health Questionnaire” (CHQ-CF87) (Helseth et al. 2006), was reduced after pump initiation (Juliussen et al. 2006). The family burden of diabetes was also measured in a prospective German study. The instruments used were the “Paediatric Inventory for Par-

ents” (PIP) (Streisand et al. 2001), and the “Hypoglycaemia Fear Survey, parent version” (HFS-P) (Clarke et al. 1998). The parents reported decreased stress and decreased fear of hypoglycaemia after pump initiation. In the study by Nuboer et al. (2008), parents perceived diabetes-specific QoL and impact of diabetes were measured with the PedsQL and DQOLY. The within-patient comparisons showed that the diabetes-specific QoL had increased and that the negative impact of diabetes had decreased after starting with CSII.

Treatment satisfaction when using insulin pumps

Adolescents who use insulin pumps have to wear them constantly. This might make their diabetes more visible, causing peers to ask questions about the pump and their diabetes.

In an earlier study among 12 CSII-treated adolescent girls aged 7-15 years at pump-start, this dilemma was investigated. After two years pump-treatment the girls expressed that the pump got in the way and it was problem to wear it with skirts and dresses (Lindholm-Olinder et al. 2007). In an interview study with 18 CSII-treated adolescents aged 11-18 years, the girls also reported fashion-related inconveniences when wearing an insulin pump (Low et al. 2005). In a Norwegian study by Juliusson et al. (2006), some adolescents reported problems with finding clothes that would keep the pump out of sight. This may lead to difficulties in using the pump. However, in these three studies the adolescents were very satisfied with the pump and did not want to switch to MDI.

In three of the randomized trials presented in Table 1, treatment satisfaction was measured using the “Diabetes Treatment Satisfaction Questionnaire” (DTSQ) (Bradley 1994). All studies showed that the CSII groups were more satisfied with the treatment than the MDI groups were (Weintrob et al. 2003, Cohen et al. 2003, Skogsberg et al. 2008). In the recently published Cochrane review comparing MDI and CSII, the data suggest that the majority of participants, both adults and adolescents, were more satisfied with CSII than MDI (Misso et al. 2010).

Parental involvement

Adolescence is the period in life when the responsibility for the self-management of diabetes should be gradually transferred from the parents to the adolescent. Three different self-management patterns can be described: parent-dominant, transitional and adolescent-dominant. These describe the degree of transfer of diabetes management responsibilities from the parents to the youth with diabetes (Schilling et al. 2006). In the literature there is a great deal of support for continued parent involvement and shared responsi-

bility for diabetes management during adolescence (Wysocki and Greco 2006). The American Diabetes Association's (ADA) practice recommendations underscore the importance of parental involvement throughout adolescence (Silverstein et al. 2005).

A higher degree of parental involvement in diabetes self-management can contribute to both better disease control and better perceived well-being. In a study among 115 adolescents Graue et al. (2005) showed that a higher degree of adolescents perceived parental care and involvement as being related to higher perceived HRQL. Helgeson et al. (2008) also support this, showing that shared responsibility appeared to be most adaptive for both psychological and physical health in a study among 132 adolescents.

The quality of the parental involvement is important. In a qualitative interview study among 32 adolescents, Viklund and Wikblad (2009) found that parental involvement could be both constructive and destructive. The constructive involvement was positive, with parents and the adolescent sharing knowledge and responsibility. When the parental involvement was destructive, with absent or authoritarian parents, humiliation or a lack of empathy, it could be a hindrance to the self-management. Destructive involvement may lead to conflicts about diabetes, which are strongly related to the disease control (Anderson et al. 2002), and to generic and diabetes-specific perceived health (Weissberg-Benchell et al. 2009). In an integrative review concerning communication between adolescents with diabetes and their parents Dashiff et al. (2008) found that support, involvement and warmth were concepts described as indicators of productive parent-adolescent communication. On the other hand, conflict, control and negative affect were described as problematic for the communication.

Rationale of the thesis

Insulin pump treatment has been used in adolescents with type 1 diabetes for approximately 30 years (Tamborlane et al. 1979). It is considered the most comparable physiological method for imitating the healthy body's insulin profile (Bangstad et al. 2009). Treatment satisfaction among adolescents is often high (Weintrob et al. 2003, Cohen et al. 2003, Skogsberg et al. 2008), and some studies have also reported increased perceived subjective health after starting with CSII (McMahon et al. 2005, Nuboer et al. 2008, Muller-Godeffroy et al. 2009). However, many adolescents have difficulty achieving the recommended disease control despite insulin pump treatment (de Beaufort et al. 2007, Danne et al. 2008, SWEDIABKIDS 2009). In a previous study we found that adolescents were satisfied with insulin pump treatment and that many of them could improve their disease control although few reached the recommended goals (Lindholm-Olinder et al. 2007). Many adolescents may find the self-management of diabetes demanding. In turn, the problems involved in managing daily treatment may result in insufficient self-management, which contributes to unsatisfactory disease control. The current thesis explores various aspects of the self-management of diabetes in adolescents using insulin pumps in order to describe conditions contributing to their achieving the recommended disease control.

Insulin pumps present unique possibilities in that they offer different methods of bolus administration for avoiding post-prandial hyperglycaemia. Previous studies have demonstrated that the dual-wave method results in less post-prandial hyperglycaemia after a pizza meal (Chase et al. 2002, Lee et al. 2004, Jones et al. 2005). Whether any single bolus dose method with a recommended main meal is superior in managing glucose levels remains to be explored.

One cause of suboptimal disease control among adolescents using CSII may be insulin omission (Burdick et al. 2004, Pankowska et al. 2005, Vanderwel et al. 2010). The interest here was to gain deeper insight into the self-management of CSII, and to explore how frequent insulin omission was among Swedish adolescents. Further, the interest was to explore relationships between insulin omission, glycaemic control and other variables such as diabetes duration, age and QoL.

Considering that adolescents with diabetes prefer CSII to MDI, it is somehow paradoxical that a high frequency of missed doses occurs with CSII. Diabetes care teams need to understand more about the problems of

missed bolus doses to be able to find strategies for educating and guiding adolescents in taking their doses. The questions raised were: “What is going on when adolescents miss their bolus doses?”, “In what situations are bolus doses missed?”, and “Are there any existing strategies for avoiding missed doses?”.

Aims

General aim

The aim of this thesis was to explore aspects of the self-management of diabetes in adolescents using insulin pumps in order to describe conditions contributing to the recommended disease control.

Specific aims

The specific aims of the different papers were as follows:

- To assess whether one method of insulin bolusing was superior to two others in managing two pasta meals and to compare the glucose levels with those of females without diabetes (Paper I).
- To investigate the management of CSII in adolescents with type 1 diabetes including their administration of bolus doses, and to study relationships between insulin omission and metabolic control, BMI, daily frequency of SMBG and bolus doses, HRQL, the burden of diabetes and treatment satisfaction (Paper II).
- To gain insight into and generate theoretical knowledge about the processes involved when insulin pump-treated adolescents take or miss taking their bolus doses (Paper III).
- To investigate reasons for missed bolus doses and strategies for avoiding this among adolescents using insulin pumps (Paper IV).

Methods

Study designs

Quantitative and qualitative designs have been used in this thesis. An overview of the designs and methods used in the different papers is presented in Table 2.

Table 2. Overview of data collection years, design, participants, data collection and analyses in the four papers.

Paper	Data collection (year)	Design	Participants	Data collection	Analyses
I	2005-2006	Crossover study	15 girls with diabetes 10 girls without diabetes age: 13-20 years	CGM Capillary blood glucose	Friedman's test Mann-Whitney U test
II	2007	Descriptive cross-sectional study	90 adolescents age: 12-18 years	Pump data HbA1c SMBG frequency BMI/BMI SDS Perceived health QoL Treatment satisfaction	Unpaired t-test Multiple linear regression analysis
III	2008-2009	Qualitative explorative interview study	12 adolescents age: 12-19 years 4 parents 1 diabetes nurse	Individual interviews 20-50 minutes	Grounded theory method
IV	2008-2009	Qualitative explorative interview study	12 adolescents age: 12-19 years	Individual interviews 20-50 minutes	Grounded theory method

Participants

Paper I

Twenty-five females were included divided into two groups. One group comprised 15 girls with type 1 diabetes, aged 13-20 years, who were regularly visiting Sachs' Children's Hospital. The other group comprised ten healthy, non-smoking girls without diabetes of the same ages, purposely sampled from different schools in Stockholm. The inclusion criteria for the former group were: female with type 1 diabetes (C-peptide < 0.25 nmol/L), treated with CSII > 6 months, aged 13-20 years, current HbA1c value below 9% (Mono-S), non-smoker and no diseases or symptoms that could be associated with delayed gastric emptying.

Power calculation (power = 80% and alpha = 0.05) indicated that it would be necessary to have 12 participants in the diabetic group to detect a difference of 2 mmol/L in glucose levels between the different bolus methods.

Paper II

Ninety participants were derived from four different paediatric diabetes clinics in Sweden. The participants were between 12 and 18 years old and had used CSII > 6 months.

Power calculation (power = 80% and alpha = 0.05) indicated that to show a 1% unit difference in HbA1c (SD= \pm 1.1) between those who do and those who do not miss bolus doses, it would be necessary to have 19 youths in each group. Burdick et al. (2004) reported that 35% did not miss their doses, which indicates a minimum of 54 participants. As we did not know the frequency of missed doses among the Swedish participants or the frequency of dropout, we decided to include 90 participants.

Papers III and IV

The participants were collected using theoretical sampling and the interview data were analysed simultaneously with new data collection as the grounded theory method had been chosen (Glaser and Strauss 1967, Glaser 1978, Strauss and Corbin 1990, Schreiber 2001). Thus the inclusion of participants was adapted to the emerging categories. We also included participants of different demographic backgrounds, as well as those who had different disease control. Adolescents who missed bolus doses with different frequencies were interviewed, the frequency ranging from very often (daily) to only occasionally (once a month). All had used a pump for at least three years. We included five males and seven females, with a mean age of 14.4 years (range 12-19), mean diabetes duration of eight years (range 4-15) and mean HbA1c of 7.9% (range 5.7-14%). The participants were regularly visiting four (of 43) different Swedish paediatric diabetes clinics and lived in towns

for the most part, with some living in the countryside. Six of the participants had parents who lived together and six had parents who were divorced.

When the core category “responsibility” emerged in Paper III, we decided to interview those who had the formal responsibility, namely some of the parents. One father and three mothers, living in different towns, were interviewed. All parents worked: one was a master of engineering, one was a teacher and two were assistant nurses. Three of the parents lived together with the other parent. Furthermore, one diabetes specialist nurse who had long experience of working with children and adolescents with diabetes was interviewed, and was asked about her experience of interaction with patients who miss bolus doses.

Intervention

Paper I

To be able to study which bolus method could be recommended to take with a recommended daily lunch, a meal which adolescents like and which is a common everyday meal had to be chosen. Pasta Bolognese with two different fat contents was chosen. The meals consisted of weighed quantities of Pasta Bolognese, milk, grated carrots and rapeseed oil. One meal contained 30 E% fat and was standardized after the recommendations (NNR 2004). The other meal had a higher fat content 36 E%. Five ml rapeseed oil was added to the portion with 30 E% fat, and 12 ml to the 36 E% portion. The two meals contained almost identical amounts of protein and carbohydrates.

At every meal the girls with diabetes administered the same total of bolus doses with their pumps, but used three different methods of bolus dosing in random order:

- Normal: 100% of the insulin dose delivered just when they started eating.
- Dual-wave: 60% of the insulin dose delivered as normal bolus dose and 40% delivered during a period of one hour.
- Square-wave: 100% of the insulin dose delivered as a prolonged bolus dose, beginning just when they started eating and continuing over the next hour.

Data collection

HbA1c

In Papers I and II glycaemic control was measured by looking at HbA1c values using a DCA 2000 apparatus (Siemens medical solution diagnostics,

Mölndal, Sweden). The values were Swedish Mono-S standard, normal reference 3.4-5.0% (compared with the DCCT's HbA1c units, the Mono-S method gives approximately 1%-unit lower results). The same DCA 2000 apparatus was used for all measures, and in Paper II all cartridges used had the same lot number.

In Paper III and IV the HbA1c values were obtained from the participants' medical records.

Blood glucose

In Paper I, glucose values were checked every fifth minute using sensors for continuous glucose measuring (CGMS®, Medtronic, Minneapolis, Minnesota, USA). The girls' blood glucose levels were also assessed using capillary measurement every half hour from 90 min before until three hours after the meal, with the Freestyle Mini™ (Abbott Scandinavia AB, Abbott Diabetes Care, Solna, Sweden).

In Paper II the participants' own blood glucose monitors in combination with their own statements gave the frequencies of SMBG; the mean frequency per day for the previous month was assessed.

Body Mass Index

BMI (kg/m^2) and BMI standard deviation scores (BMI SDS) (Rolland-Cachera et al. 1982) were calculated from the participants' weight (kg) and height (m), measured in connection with the study in Papers I and II.

Insulin pump data

In Paper II data from all pumps were downloaded to a computer, and the frequency of bolus doses and the basal dose for the day under study were assessed from the downloaded pump data. The mean frequency of daily bolus doses and the total mean insulin dose (basal and bolus) per day for the previous four weeks were also registered.

Perceived health and QoL

Disabkids questionnaire

In Paper II, perceived health was measured using Disabkids (chronic-generic and diabetes module) (Baars et al. 2005, Simeoni et al. 2007).

The Disabkids questionnaires were developed in a European cross-cultural multi-centre study, to measure perceived health and QoL in children with chronic conditions. Their reliability and validity have been tested, and have been found to be satisfactory (Baars et al. 2005, Simeoni et al. 2007).

The Disabkids chronic-generic module measures perceived mental, social and physical health in six dimensions: independence, emotion (inner strength), social inclusion, social exclusion (equality), physical limitation (physical abilities), and medication (treatment) (the names of some dimension have recently been changed (Chaplin et al. 2009); and the new names are presented within parentheses). The scores from the six dimensions are combined to get a total score for general health. The chronic-generic module consists of 37 items. The Disabkids diabetes module has two dimensions, one concerning impact that measures emotional reactions to diabetes treatment and one concerning treatment that measures the burden of carrying equipment and planning treatment. The diabetes module consists of ten items. The scores for both the chronic-generic and the diabetes dimensions are given on a 5-point Likert scale, and transformed into a range from 0 to 100; higher scores indicate better perceived health (Bullinger 2006).

Check Your Health

In Paper II, Check Your Health was used to measure perceived health, QoL and impact of diabetes. It consists of four double-scaled thermometers graded 0 to 100 (with 0 indicating low perceived health), and gives a picture of perceived physical, emotional and social health and QoL.

On each of the four scales, the person reports perceived and imagined health/QoL if he/she had not suffered from diabetes. The measured difference between the perceived and the imagined health/QoL without diabetes is defined as “the impact of diabetes” and can range from 0 to 100. When the difference of results was a negative value, meaning that imagined health/QoL without diabetes was reported to be lower than health/QoL with diabetes, the impact was interpreted as zero.

Check Your Health has been tested in adults with both type 1 and type 2 diabetes and in teenagers with type 1 diabetes, and its reliability and validity have been found to be satisfactory (Wikblad 2003, Viklund and Wikblad 2010).

Treatment satisfaction

In Paper II, treatment satisfaction was measured with the single question: “How satisfied are you with your current treatment?” Answers were given on a Likert scale, graded 0-6, with higher scores indicating better treatment satisfaction.

Individual interviews

The interviews in Papers III and IV were conducted by the author, and were tape-recorded and immediately transcribed. Open-ended questions covering different aspects of the problem of missed doses as well as follow-up ques-

tions were used. The participants were encouraged to speak freely. Topics brought up spontaneously in early interviews were raised in subsequent interviews and questions were adapted according to the emerging categories. The data collection continued until we had reached a saturation point, when new data yielded redundant information, in line with the grounded theory method (Glaser and Strauss 1967, Glaser 1978, Strauss and Corbin 1990, Schreiber 2001).

Procedures

Paper I

The girls with diabetes consumed each of the two lunches on three occasions, eating a total of six lunches. The girls without diabetes consumed the two lunch meals on two different days.

Both groups came to the clinic three hours before the meal and had sensors for CGM inserted into the subcutaneous tissue in the lateral flank or the abdomen. They remained at the clinic, without exercising or eating anything except the standardized meal, until three hours after the meal.

All were asked to perform the same type of physical activities the day before the study days and to eat the same type of breakfast before arriving at the clinic.

Paper II

The participants were asked about participating when they were called for their regular visit to the diabetes clinic. The researcher met the participants in connection with this visit, and all data were obtained during the one visit.

To conclude whether or not insulin omission had occurred, the adolescents made a list of what they had eaten the day before their visit. They also filled in the amount of bolus dose they thought they had taken, or should have taken, with each meal or snack. At the same time, data from their pumps were downloaded. The researcher and the adolescent then together compared the list with the downloaded pump data. This made it possible to assess the frequency of missed bolus doses, and the percentage of missed bolus doses from the previous day was calculated.

Papers III and IV

The participants were asked by their diabetes nurse to participate in the interview study and all were positive about being interviewed. The interviewer then contacted them by telephone and a time and place for the interview was determined.

The participants could choose the place for the interview, and most interviews were conducted at the various paediatric diabetes clinics although

some were conducted at the participant's home. The interviews were informal and lasted between 20 and 50 minutes.

Quantitative data analyses

In Papers I and II data were analysed using the Statistical Package for social Sciences (SPSS) software (versions 12 and 14). The level of statistical significance was set at $p < 0.05$.

Paper I

Non-parametric statistics were used, as the data were skewed. Blood glucose change, time to reach maximal glucose peak, maximal peak and area under the glucose curve (AUC) (Altman 1991) were evaluated from both the capillary glucose values taken every half hour and the CGM values tracked every fifth minute. Friedman's test was used to compare the different bolus methods for the different meals in the diabetic group. The Mann-Whitney U test was used to compare the glucose excursion between the females with diabetes and the females without diabetes (Table 2).

Paper II

The participants were divided arbitrarily into two groups: those who had missed $\leq 15\%$ (less than 1 in 7) of the bolus doses the previous day and those who had missed $> 15\%$. An unpaired t-test was used to compare the groups. Stepwise multiple linear regression analysis (backward and forward selection) was used to examine which variable (age, diabetes duration, pump therapy duration, BMI SDS, frequency of bolus doses, frequency of SMBG, total insulin dose U/kg, percent basal dose, perceived health, impact of diabetes, treatment satisfaction) contributed the most to glycaemic control, measured as HbA1c (Table 2).

Qualitative data analyses

The questions raised were: "What is going on when adolescents miss their bolus doses?", "In what situations are bolus doses missed?" and "Are there any existing strategies for avoiding missed doses?". In an attempt to answer these questions, the grounded theory method was chosen as a model for the collection and analysis of data. The method was developed by Glaser and Strauss (1967) and has been further developed in different directions by Glaser (1978), (1998), Strauss and Corbin (1990), and other researchers (Schreiber 2001).

According to Glaser (1978, p. 93), the goal of grounded theory is "to generate a theory that accounts for a pattern of behaviour which is relevant and

problematic for those involved”. The researcher’s task is to discover and conceptualize the essence of complex interactional processes, with the intention to create a theory or model that describes or explains what is going on in the substantive area under study. The theory should be generated and grounded in the collected data, in contrast to a logical deductive theory, which is built on prior assumptions. The data are coded on different levels into conceptual categories, which are suggested by the data themselves. The data collection and analysis are carried out side by side, and data are continuously compared in the search for core features (Glaser and Strauss 1967, Glaser 1978, Strauss and Corbin 1990, Glaser 1998, Schreiber 2001).

The theory must fit and work, which means that it must be able to explain or interpret what is happening in the area under study and also that it has to be recognizable to the participants. The theory must also have grab, which means that it must have practical relevance. A grounded theory is a suggested theory rather than a proven one, and it must be possible to modify it with new data (Glaser 1978).

Papers III and IV

The analyses have been carried out according to the original grounded theory (Glaser and Strauss 1967), as well as to the description of grounded theory by Schreiber et al. (2001).

The interviews were listened to and read through several times and were consecutively analysed. Initially the data were coded line by line, the developed codes were sorted into preliminary categories, and new data were continuously compared with categories that had already emerged. The categories were scrutinized, and similar categories were combined. Two core categories emerged during the analysis of the interviews, and as Schreiber (2001) describes, we had to either select one for further examination or take one first and the other later. We chose to first analyse the core category “responsibility” (Paper III). We then analysed the other one, “lost focus” (Paper IV). When the core categories had emerged, the continued data collection and analysis were more focused on these categories.

Throughout the study, theoretical and methodological notes in diary form described as “memos” (Glaser and Strauss 1967, Glaser 1978, Strauss and Corbin 1990, Schreiber 2001) were taken by the first author; these helped in the progress of the study.

Rigour

We strived to achieve credibility by having the participants take an active role in the interviews. To increase transferability we included participants of different demographic backgrounds and participants with different levels of glycaemic control.

All interviews were read by the members of the research team. The analyses were discussed and validated within the team.

The findings presented in Paper III were presented to a diabetes team as well as to some of the interviewed adolescents and their parents to test whether it might “fit, work and have grab”, which are credibility criteria for a grounded theory (Glaser and Strauss 1967, Glaser 1978, Strauss and Corbin 1990, Schreiber 2001).

To validate the results in Paper IV, seven 17-year-old adolescents (3 females and 4 males) with many years' experience of CSII treatment were asked to make notes about reasons for missed doses and strategies for remembering them. At the time, the seven adolescents were participating in a diabetes camp arranged by one of the paediatric diabetes clinics. The adolescents' written notes were discussed with them and compared with the categories that had emerged from the interviews, and their opinions could validate the categories. The results were also validated in discussions with some diabetes health care providers as well as with some of the interviewed adolescents and their parents.

Ethical considerations

All studies have been approved by the Ethical Review Board in Stockholm (Dnr 2005/631-31/3) and Uppsala (2007/007), respectively. The participants were given written and oral information about the study that concerned them, and were informed that their participation was voluntary and that they had the right to stop participating at any time. They were also informed that all data would be treated in confidence and that findings would not be able to be linked to specific persons. All participants (and their parents, if the participant was <18 years old) gave written consent before participating in the studies.

Information about the results of the studies will be presented to the participants and their families in the form of the Swedish summary of the thesis.

None of the studies entailed any risks or possible complications. The insertion of the CGM sensor (Paper I) can hurt a bit, and the participants were offered the option of receiving a local anaesthetic cream (EMLA®).

Before each interview, the interviewer checked an extra time that the participant did not mind the interview being tape recorded. During the interviews the participants were encouraged to speak freely, but were not unduly pressed to talk about matters they were reluctant to discuss. The interviews may have raised different feelings, and the participants were encouraged to contact the interviewer or their diabetes nurse if they had questions or wanted to discuss something further.

Results

Three methods of insulin bolusing (Paper I)

Three different methods of bolusing – normal, dual-wave and square-wave – were tested in conjunction with two pasta meals with different contents of fat (30 E% and 36 E%) in 15 female adolescents with diabetes. Their post-prandial glucose excursions were compared with those of ten females without diabetes after the same meals.

There were no differences between the different methods of bolusing in time to reach blood glucose peak, peak of glucose or area under the glucose curve (AUC).

After the 30 E% fat meal, there was a difference in capillary glucose increase between the bolus methods, found at one point in time. From start to 60 min, the square-wave method gave a higher glucose increase (4.6 ± 2.8 mmol/L vs. 2.8 ± 1.7 mmol/L for normal method and 2.9 ± 2.4 mmol/L for dual-wave method, Friedman's test, $p=0.018$) (*Figure 2*).

After the 36 E% fat meal there were no significant differences in glucose increase at any time (*Figure 2*).

The variability in time for the blood glucose peak, the blood glucose peak itself and AUC was much greater among the girls with diabetes than among those without, which made it difficult to compare the groups. However, when pooling the three methods of bolusing for the 30 and 36 E% fat meals, respectively, the peaks were lower and occurred earlier among the girls without diabetes; these girls also had a smaller AUC.

All the girls without diabetes had post-prandial capillary glucose peaks below 9.4 mmol/L. In the diabetic group, the post-prandial glucose peaks were ≤ 10 mmol/L in 38 of 79 measurement cases regardless of method.

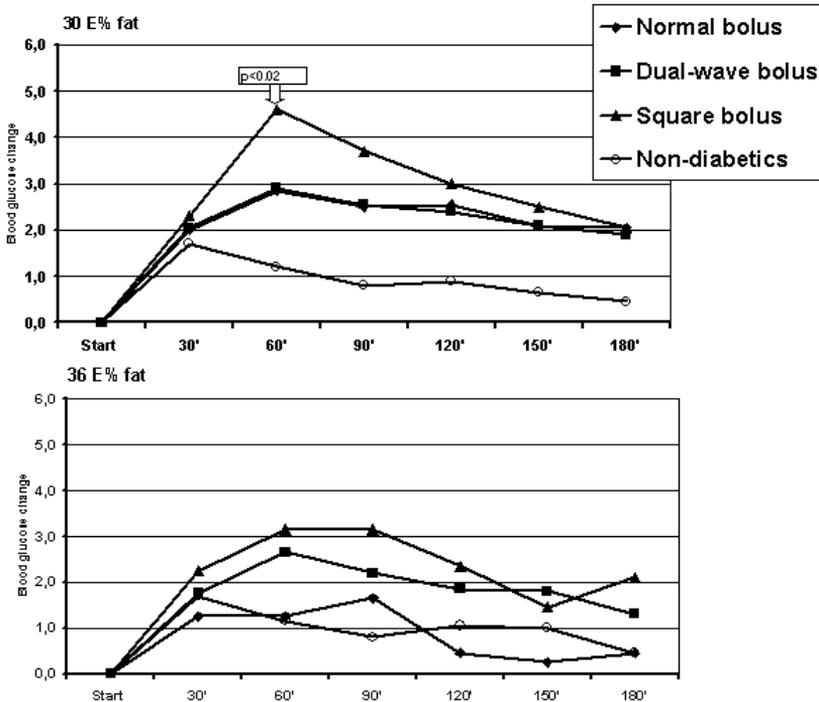


Figure 2. Capillary blood-glucose change in mmol/L for the girls with and without diabetes after the 30 and 36 E% fat meals. The arrow indicates where the square-wave bolus caused a significant higher blood glucose increase.

Missed bolus doses (Paper II)

Sixty-two per cent of the adolescents (56/90) had missed $\leq 15\%$ (less than one of seven) of the bolus doses the day before the data collection, and 38% (34/90) had missed more. The frequency of bolus doses taken the previous day correlated with the mean frequency of daily bolus doses taken during a period of four weeks (Pearson: $r=0.67$, $p<0.001$).

The adolescents who had missed $\leq 15\%$ ($n=56$) of the bolus doses had the same age, diabetes duration, BMI, BMI SDS and insulin dose per kilogram as did the group who had missed more bolus. Boys and girls had missed with similar frequencies.

Those who had missed $>15\%$ ($n=34$) of the bolus doses had higher HbA1c values ($7.8 \pm 1.2\%$ vs. $7.0 \pm 1.0\%$, $p=0.001$), took fewer daily bolus doses (3.8 ± 1.7 vs. 5.3 ± 1.7 , $p<0.001$) and fewer daily SMBG (2.4 ± 1.8 vs. 3.6 ± 1.8 , $p=0.003$), and had a higher percentage basal rate ($65 \pm 14\%$ vs.

55±12%, p=0.001). There was a tendency that those who missed more had been using pump therapy for a longer period of time (3.9±1.9 years vs. 3.1±1.8 years, p=0.07).

Multiple linear regression analyses showed that the variations in HbA1c values could be independently explained by the frequency of SMBG per day (p<0.0001) and the frequency of bolus doses (p=0.013) adjusted for duration and age (R²= 0.339, p<0.0001).

The group who had missed >15% of the bolus doses the previous day scored lower on perceived health in the medication (treatment) dimension in the Disabkids chronic generic questionnaire (72.1±17.9 vs. 79.7±14.0, p=0.040, scale 0-100, with higher scores indicating better perceived health). They experienced a greater emotional impact when taking their insulin dose, and perceived their regimen as an interruption of their everyday life. The Disabkids diabetes module showed differences between the groups in two sub-questions. Those who missed >15% of the doses perceived that diabetes ruled their days more (69 vs. 78.2, p=0.038) and were more fed up with measuring blood sugar levels (44.8 vs. 58.6, p=0.008).

Measuring the impact of diabetes with Check Your Health indicated an overall low impact among the adolescents; with mean scores between 1.8 (social burden) and 7.4 (physical burden) (scale: 0-100), there were no differences between the groups.

The adolescents were satisfied with the insulin pump treatment. However, those who had missed ≤15% of the doses were slightly more satisfied with it (5.3±0.7 vs. 4.8±1.1, p= 0.029, scale: 0-6, with higher scores indicating higher treatment satisfaction).

Clarifying responsibility (Paper III)

The analysis of the collected data revealed the need to clarify the responsibility for diabetes self-management in continuous negotiations between adolescents and parents to avoid missed bolus doses. A mutual agreement between adolescents and their parents that negotiations about this responsibility are allowed may impede some of the excited discussions regarding the self-management of diabetes. Ways of solving everyday problems differ between families. The diabetes care team, including the diabetes specialist nurse, can encourage and support these negotiations.

Responsibility is the core category that emerged which, in the context of taking or missing bolus doses, can be explained by the three subcategories distribution of responsibility, transfer of responsibility and clarification of responsibility.

The distribution of the responsibility for diabetes self-management was clearer among those who missed fewer doses; these adolescents either had a high level of personal responsibility or shared it with their parents. On the

other hand, there was a lack of responsibility among those who missed many doses. In this case the adolescent's own responsibility was low and no one covered for this deficiency, causing bolus doses to be missed.

The optimal transferral of responsibility is when it gradually moves from the parents to the adolescent. The adolescent's responsibility can decrease or increase, and an ongoing negotiation about this is necessary. Sometimes the adolescent can assume more responsibility for a while. Taking more responsibility means more freedom; they can do more things on their own without losing control over the diabetes.

Adolescents and parents need to negotiate and clarify the responsibility for the diabetes self-management, which also includes taking bolus doses, and this negotiation needs to be continuous. A model of a practical tool to facilitate the negotiation is illustrated in *Figures 3 and 4*. The adolescent can indicate the level of responsibility they are ready to take, and it is then possible to negotiate who should cover for what is lacking. The diabetes care teams have the task of supporting and encouraging these negotiations; this can be facilitated with the tool.

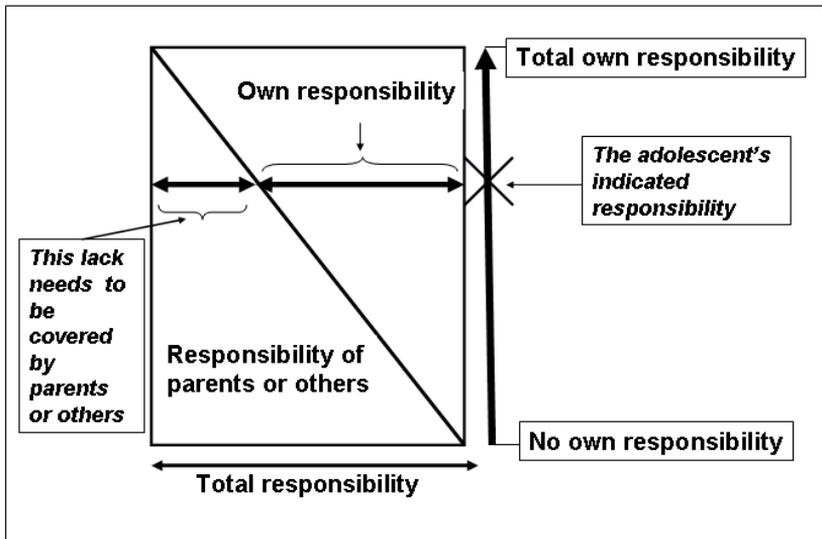


Figure 3. A model of a practical tool to facilitate the clarification of responsibility for the diabetes self-management in adolescents. The box is divided into two parts: *Own responsibility* and *Responsibility of parents or others*. The adolescent indicates his/her own responsibility, and it is then possible to negotiate who should cover for what is lacking. An example of an adolescent's responsibility is given in italics. On the next page, the plain model is illustrated in *Figure 4*.

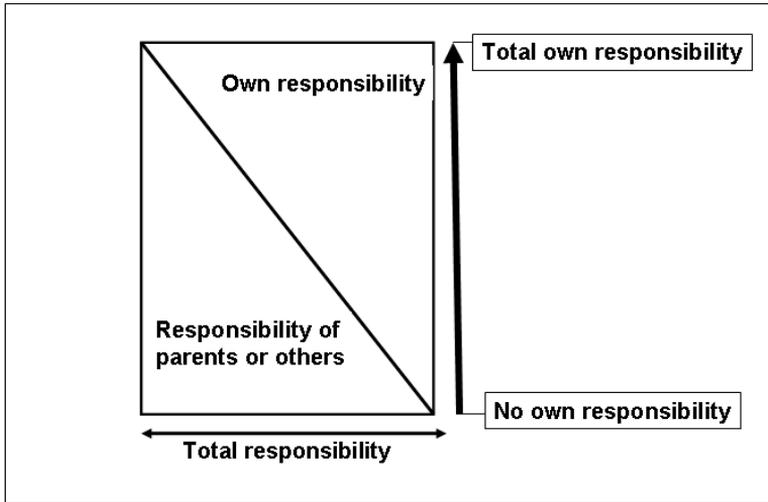


Figure 4. A plain model of the practical tool, to be used to facilitate the clarification of responsibility for the diabetes self-management in adolescents. See also *Figure 3*.

Missed bolus doses – “lost focus” (Paper IV)

In the analysis of the transcribed interviews, the category “lost focus” emerged as the main reason why adolescents missed taking bolus doses. Identified subcategories were “delayed lost focus”, “directly lost focus” and “totally lost focus”. The category “agreements involving reminders” appeared to be the main strategy for avoiding missed bolus doses. Subcategories were identified as personal and technological reminders.

Delayed lost focus refers to the adolescent intending to take the bolus dose after the meal (so-called post-prandial bolusing), but then forgetting to do so. Some adolescents always used post-prandial bolusing, but most of them only used it in special situations. Three situations were identified in which post-prandial bolusing was used: to avoid hypoglycaemias, embarrassment at letting others see the pump, and inconvenience of the pump’s location.

Directly lost focus is when focus on the bolus dose is lost directly in connection with the start of the meal. Something happens which results in lost focus and a missed bolus dose. The stressful situation during school lunches was an occasion when it was easy to lose focus.

Totally lost focus occurred when the adolescents did not have the strength to maintain focus on diabetes self-management, and missed taking bolus doses. This occurred when the adolescents perceived the negative impact of diabetes as too high. They felt overwhelmed and did not have the strength to

care about themselves. Several SMBGs resulting in high glucose levels could contribute to this condition. Another type of totally lost focus was when adolescents did not bother at all with their self-management and seemed to ignore the fact that they had diabetes.

The consequences of lost focus can be seen as a vicious circle (*Figure 5*). Lost focus causes missed bolus doses. This causes high plasma glucose levels, which in turn may lead to a high negative impact of diabetes and neglecting diabetes, which can lead to totally lost focus and more missed bolus doses and impaired glycaemic control, and so on.

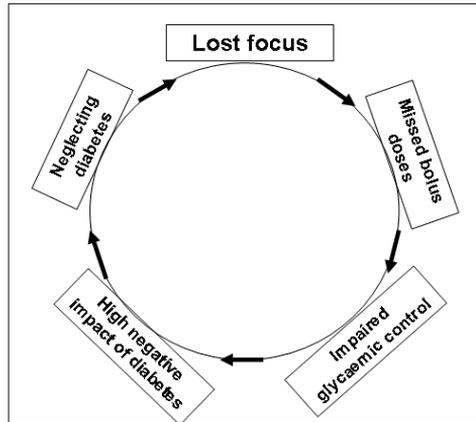


Figure 5. The consequences of lost focus described as a vicious circle. Lost focus causes missed bolus doses, which cause impaired glycaemic control, which can cause a high negative impact of diabetes and neglecting diabetes, which in turn cause lost focus.

Adolescents who took most of their doses did it as a routine; they did not think about it much. These adolescents recommended taking the dose in connection with the start of the meal to avoid missed bolus doses. Others needed agreements involving reminders to remember their bolus doses. It was crucial that the adolescent be involved in these agreements; otherwise, the reminders were seen as nagging and did not work. The adolescents said that they needed to take the dose directly after the reminder, as they easily forgot things immediately. Parents, friends, parents of their friends, and teachers could help them remember to take the bolus doses. The adolescents appreciated having these personal reminders, but could sometimes feel like they were being controlled and could experience the reminders as nagging.

A personal rather than technological reminder was preferred. Technological reminders seemed to work for shorter periods of time; this could be useful during stressful periods. Some adolescents had used continuous glucose measuring (CGM) for a couple months, and experienced that it worked as a technological reminder and helped them detect missed doses earlier.

Discussion

General discussion

This thesis has explored aspects of the self-management of diabetes in adolescents using insulin pumps in order to describe conditions contributing to achieving the recommended disease control.

The main results of the thesis describe that individual bolus dose testing, clarification of the responsibility for the self-management and agreements involving reminders to remember bolus doses are conditions which may contribute to achieving the recommended disease control. The thesis also describes that lost focus and a lack of responsibility can lead to insulin omission and be a hindrance to achieving recommended disease control. These conclusions are illustrated in *Figure 6*.

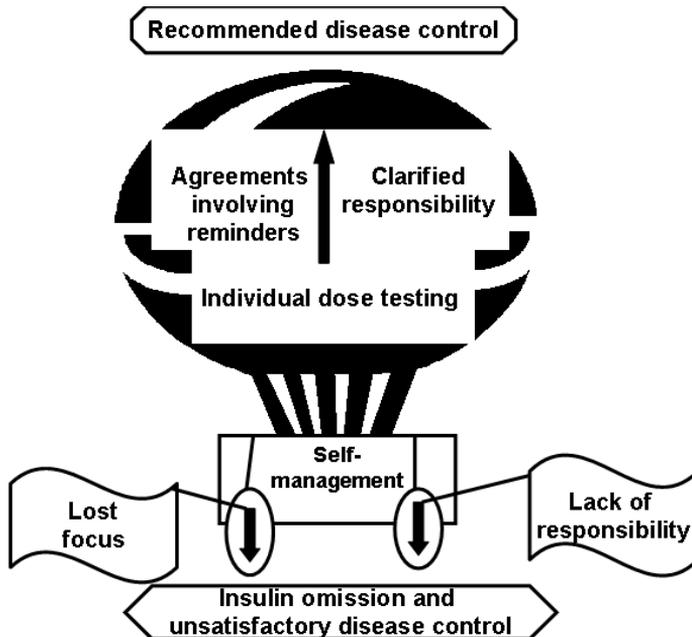


Figure 6. An illustration of the conclusions of the thesis. The self-management is illustrated as a hot-air-balloon. The balloon lifts and reaches the recommended disease control with the conditions listed in the balloon. The sandbags, “Lost focus” and “Lack of responsibility” cause the balloon to descend to insulin omission and unsatisfactory disease control.

The different papers will be further discussed under the subheadings: self-management; diabetes disease control; health, well-being, QoL and treatment satisfaction; and parental involvement.

Self-management

There are several explanations, both physiological and psychological, for the variations in HbA1c values in adolescents, one of which could be insufficient self-management (Rewers et al. 2009, Court et al. 2009). Among the adolescents studied in Paper II, more than a third of the variations could be explained by the frequency of the self-management activities of taking bolus doses and performing SMBG. At least theoretically, it is possible to solve this problem through education and motivation in order to increase the frequency of bolus doses and SMBG. However, education seems to be difficult in adolescents. Murphy et al. (2006) have reviewed studies on diabetes education for children, adolescents and their parents published after 2001 and concluded that the effect on disease control and psychosocial factors was low.

It has to be remembered that taking a bolus dose involves more than simply pressing the button on the pump. Adolescents have to calculate the most appropriate insulin dose in relation to different types of food, reflecting on their blood glucose levels and different types of activities. Those included in Paper II, who missed more doses perceived a greater negative emotional impact when taking their insulin doses. They also perceived it as an interruption of their everyday life and were also more fed up with SMBG. The adolescents included in Paper IV reported that inconvenience of the pump location and feelings of embarrassment to show the pump could result in missed bolus doses. These findings are in line with Spencer et al. (2009), who describe how adolescents can perceive these self-management activities as inconvenient and disruptive. Some also receive unwanted attention when injecting and testing in public places.

The relationship between these self-management activities and the disease control is also shown in other studies. The importance of frequent bolusing has been shown in the PedPump study, in which pump data and HbA1c values from 1 041 pump-treated children and adolescents from 17 different countries were recorded. The study showed a correlation between HbA1c and the frequency of daily bolus doses, while there was no correlation between HbA1c and the total daily insulin dose. The use of less than seven bolus doses per day was a predictor of an HbA1c value above the recommended value (Danne et al. 2008).

The importance of SMBG has also been shown by other researchers. Plotnick et al. (2003) studied data from 95 pump-treated children and adolescents, and found that a higher frequency of SMBG together with greater parental involvement and shorter duration of diabetes were associated with

lower HbA1c. Wood et al. (2006) found that adolescents who terminated insulin pump therapy had a lower frequency of SMBG and higher HbA1c values. All participants included in Paper II had been advised to take four SMBGs per day whilst in fact the majority of them carried out fewer tests. These findings indicate the necessity for diabetes care teams to provide new strategies for educating and motivating youths to perform SMBG. But, again, this seems to be difficult. Existing education programmes show low effect on disease control, despite different approaches (Murphy et al. 2006, Viklund 2008).

As highlighted in Paper IV, the main reasons for missed bolus doses from the adolescents' perspective was categorized as lost focus, with the three subcategories delayed lost focus, directly lost focus and totally lost focus. The reasons found are in congruence with those found in the study by Burdick et al. (2004); directly lost focus can be similar to "forgetting". Among the situations noted for post-prandial bolusing which resulted in delayed lost focus, we can recognize two other reasons found by Burdick et al.: "Inconvenience with the pump locations" and "Avoiding hypoglycaemia". The reason "Being too busy", found by Burdick et al., may be the same as the experience categorized as totally lost focus, when the adolescents neglect their diabetes, described in the quote: *"I don't think about having diabetes then, I want to be like everyone else, don't want to have diabetes. Sometimes I might miss on purpose but not so often. You cannot run while you are taking it. In school we often play around and you cannot run and take it at the same time"*.

The category "delayed lost focus" in Paper IV occurred when the adolescent for different reasons, used post-prandial bolusing. The possibility for adolescents to take rapid-acting insulin analogues after a meal has previously been reported as a safe and effective alternative compared to pre-prandial bolusing (Danne 2007). However, post-prandial bolusing is seldom clinically motivated in adolescents, as can be the case in younger children whose carbohydrate intake can be uncertain (Smart et al. 2009). In a recently conducted Italian study, Scaramuzza et al. (2010) investigated the optimal timing of bolusing in 30 adolescents and found that injecting insulin just after a meal resulted in a higher blood glucose increase after 60 minutes. The author concluded that injecting just before or 15 minutes before a meal were the most preferable timings. In another recently published study among 23 adolescents, it was shown that bolusing 20 minutes before a meal was the most preferable time; there was no difference between bolusing just before or 20 minutes after the meal (Cobry et al. 2010). According to the adolescents included in Paper IV, one advantage of injecting before the meal is that it is easier to remember the dose then.

A frequently cited reason for insulin omission is weight control (Neumark-Sztainer et al. 2002). Paper II could not identify any differences in BMI or BMI SDS between the group who had missed more bolus doses and the group who had missed very few. Weight control could not be identified

as a reason for insulin omission in Paper IV, although the interviewer tried to ask questions to cover this. Perhaps the adolescents did not dare to admit this behavior, although it has been found to be more common among older females. In a study concerning disturbed eating behaviours in younger girls (n=98, age at baseline: 11.8±1.5 years) who were followed for five years, insulin omission was more unusual. The authors reported that 49% had disturbed eating behaviours, although only 3% reported insulin omission to control their weight (Colton et al. 2007).

The adolescents included in Paper IV preferred personal reminders about bolus doses, and often appreciated it when their parents or others assisted them through reminders. Technological reminders like alarms in the pump had been used for shorter periods of time, but for longer periods the adolescents seemed to ignore them. This finding is in line with results from a study by Chase et al. (2006), wherein the effect of meal bolus alarms in the pumps was studied in a randomized trial among 47 CSII-treated adolescents. In the group using alarms, the HbA1c values improved slightly and the number of missed doses decreased over a period of three months. After six months, however, there was no reduction in HbA1c values, although there was a small reduction in the number of missed bolus doses. The authors concluded that the effect of meal bolus alarms was modest and transient.

Diabetes disease control

Any overall differences in managing the post-prandial glucose control between different methods of bolusing with pasta meals were not proven in Paper I. Based on this study, no single method of giving bolus doses can be recommended as superior in managing a recommended main meal.

Heinemann (2009) has performed a critical evaluation of studies exploring the impact of different bolus methods on post-prandial glucose levels. He claims that all studies have shortcomings in design and performance, and states that the recommendations in these studies have to be accepted with care. To be able to give meaningful results, meal-related studies must pay attention to many aspects.

Three previous studies have shown that the dual-wave method can be recommended with pizza meals (Chase et al. 2002, Lee et al. 2004, Jones et al. 2005). In a more recently published study, the dual-wave method was compared to the normal bolus method with two recommended meals in 20 adolescents with diabetes. Each meal had a different glycaemic index (GI). The best choice for a recommended meal with a low GI was the dual-wave method, which gave fewer hypoglycaemias. With a normal bolus the blood glucose levels decreased too much. For a recommended meal with a high GI, there was no difference between normal and dual-wave bolus methods (O'Connell et al. 2008). The meal with a low GI had a GI value comparable to those in our study, but the fat contents were much lower in the study by

O'Connell et al. (2008) than in our study, the fat content in their study seems to be lower than the recommended 30 E%. The different fat contents make it difficult to compare the studies, as gastric emptying is dependent on the fat content (Frost et al. 2003).

Our results indicated that the square-wave method gave a higher glucose increase after consumption of the less fatty pasta meal and may be less favourable. This result is in line with Chase et al. (2002), who also found that the square-wave method gave the highest glucose increase after a pizza meal.

Compared to one hour in our study, the dual-wave bolus dose was extended for a longer period in the other studies. It was extended to two hours in the studies by Chase et al. (2002) and O'Connell et al. (2008), to an average of 5.2 hours in the study by Lee et al. (2004), and to four or eight hours in the study by Jones et al. (2005). Like our study, the two latter ones found no differences between the methods of dosing during the first three hours after the meal, though after four hours the dual-wave method resulted in a lower mean glucose value (Lee et al. 2004, Jones et al. 2005).

A clinically important finding in Paper I is that in nearly half of the measurements it was possible to achieve normoglycaemic post-prandial levels in the adolescent girls with diabetes regardless of bolus dose method. This indicates that adolescents can be encouraged to test which bolus method gives the most normal post-prandial glucose levels with different meals.

Paper II showed that insulin omission was common. More than a third of the adolescents had missed bolus doses the day before their visit to the diabetes clinic. This result is in congruence with three other studies reporting on the frequency of insulin omission (Burdick et al. 2004, Pankowska et al. 2005, Vanderwel et al. 2010). In the current study, as well as in those by Burdick et al. (2004) and Pankowska et al. (2005), the frequency of missed doses correlated with the disease control. In the study by Vanderwel et al. (2010), insulin omission with afternoon snacks was investigated, and was found to be common and to result in high glucose excursion.

Another finding in Paper II was that those who missed more doses had a higher percentage basal rate but the same total daily insulin dose. This is in congruence with the PedPump study, including 1,041 pump-treated children and adolescents from 17 different countries, in which there was a correlation between HbA1c and the percentage of basal rate whilst there were no correlation between HbA1c and the total daily dose (Danne et al. 2008). The basal rates may have been increased to adjust high blood glucose values, perhaps without the carers knowing that there were missed bolus doses. This highlights the importance of downloading the insulin pump history as adolescents are often unaware of their insulin omission, or underestimate its frequency (Burdick et al. 2004).

Some adolescents included in Paper IV had used CGM, which they perceived as helpful in avoiding insulin omission. Previous studies have shown

that some adolescents seem to perceive difficulties with using CGM. In a randomized trial, among 322 adults, adolescents and children, only 30% of the adolescents used CGM for six or more days per week during the 26 weeks trial, however a decrease in HbA1c was reported among those who had used the CGM continuously (Tamborlane et al. 2008, Beck et al. 2009).

One question often discussed is whether treatment with CSII is the adequate treatment when the self-management is insufficient with, for example, frequent insulin omission. However, the self-management with MDI is also demanding and it is likely that adolescents would miss bolus doses even with MDI. But the risk for acute complications, such as ketoacidosis, due to lack of insulin may be greater with an insulin pump (Hanas et al. 2009, Wolfsdorf et al. 2009), although adolescents often want to keep their insulin pumps (Maniatis et al. 2001, Lindholm-Olinder et al. 2007). Diabetes care teams must be honest about the risks and discuss this problem with the adolescents and their parents. Perhaps the wish to keep the insulin pump can motivate the adolescent to assume more responsibility and take bolus doses more frequently, at least for a short period of time. Adolescents also need parental involvement, with negotiations to clarify the responsibility and agreements involving reminders (Paper III and IV). Another important issue among these adolescents is good support from the diabetes care team (Pihoker et al. 2009, Sjöblad 2008).

Health, well-being, QoL and treatment satisfaction

The adolescents included in Paper II who missed more bolus doses perceived poorer health in the medication (treatment) domain measured with Disab-kids. These adolescents perceived a greater negative emotional impact when taking their insulin doses and perceived it as an interruption of their everyday life. This perceived negative impact of diabetes treatment may have contributed to insulin omission, or the insulin omission may have contributed to a negative impact of diabetes. The insulin omission contributed to an unsatisfactory disease control; those who had missed more doses also had higher HbA1c-values. The relationship between a higher perceived negative impact of diabetes and unsatisfactory disease control was shown in a quantitative study among 199 Swedish adolescents (Viklund and Wikblad 2010). Other studies have explored the correlation between disease control (measured by examining HbA1c values) and QoL in adolescents with diabetes. Some studies report an association between higher QoL and more satisfactory disease control (Hoey et al. 2001, Hanberger et al. 2009), while others do not report any association (Graue et al. 2005). However, the causality between disease control and QoL is not known. Does good disease control increase QoL or does a high QoL enhance good disease control, or both?

The adolescents included in Paper IV reported that if high blood glucose values were the results of the performed SMBG, this could lead to unwill-

ingness to measure the blood glucose. They did not have the strength to bear all the high blood glucose values, and felt it was too much and could completely lose their focus on the self-management, also resulting in insulin omission. These results are in line with a qualitative interview study among 32 adolescents, which reported that the adolescents had feelings of hopelessness when their blood glucose was high and hard to control. These feelings could affect their motivation to perform proper self-management. The adolescents felt relieved when their parents could help them in these situations (Karlsson et al. 2008). If the responsibility for the self-management is clarified through continuous negotiation, situations of totally lost focus might be prevented (Paper III). If adolescents who perceive a high impact of diabetes get inadequate help they are at risk of developing diabetes burnout, which is a condition characterized by feelings of guilt and hopelessness due to failure in their diabetes self-management (Anderson and Wolpert 2004).

Adolescents might want to be actively involved in the adolescent culture instead of standing out and being different. Their priority is not diabetes (Dickinson and O'Reilly 2004), which is why some of them try to ignore the fact that they have it, resulting in insufficient self-management. These adolescents perhaps do not have the strength to take responsibility for the self-management, which results in missed bolus doses and totally lost focus. Having inner strength increases the willingness to shoulder responsibility for oneself and others. Adolescents with a higher level of inner strength can perhaps take more responsibility for self-management. Inner strength can be understood through the dimensions connectedness, firmness, flexibility and creativity. If the diabetes care team is aware of the different dimensions of inner strength and supports an increase in them, adolescents may be helped to use their own resources to manage to take responsibility (Lundman et al. 2010).

Overall, the adolescents included in Paper II were very satisfied with their diabetes treatment, although those who had missed more doses reported slightly lower satisfaction. This result is in congruence with other studies in which treatment satisfaction in CSII-treated adolescents has been reported as high (Cohen et al. 2003, Weintrob et al. 2003, Low et al. 2005, Juliusson et al. 2006, Lindholm-Olinder et al. 2007, Skogsberg et al. 2008, Misso et al. 2010).

Parental involvement

The definition of self-management of type 1 diabetes in children and adolescents suggested by Schilling et al. (2002) emphasizes the importance of having shared responsibility between adolescents and parents. Paper III adds the need to clarify this shared responsibility. Diabetes care teams can encourage and support negotiations between parents and adolescents to clarify the responsibility for self-management.

Parental involvement is important, especially as the self-management of diabetes is demanding for an adolescent. Several studies, as well as recommendations from the American Diabetes Association (ADA), express the importance of parental involvement (Anderson et al. 2002, Schilling et al. 2002, Graue et al. 2005, Silverstein et al. 2005, Wysocki and Greco 2006, Helgeson et al. 2008). A recently published cross-sectional study among 252 adolescents (age 10-14 years) with diabetes, found that parental involvement could prevent a deterioration of the disease control after pump initiating (Wiebe et al. 2010). Viklund et al. (2007) studied empowerment education among 32 adolescents and found a decrease in HbA1c values among those who had involved parents more in the education programme; the authors concluded that empowerment programmes for adolescents with diabetes should include parental involvement. There is a need to further elaborate effective education programmes for adolescents with diabetes and to include parental education in these programmes (Murphy et al. 2006).

Parental involvement can be both constructive and destructive (Viklund and Wikblad 2009). The adolescents included in Papers III and IV reported that parental involvement could sometimes be perceived as nagging, which is also described by others (Kyngas and Barlow 1995, Dickinson and O'Reilly 2004). This nagging often results in conflict, which can impair the disease control (Anderson et al. 2002) and decrease generic and diabetes-specific perceived health (Weissberg-Benchell et al. 2009).

The finding revealed in Paper III, regarding the need to clarify the responsibility for the self-management between parents and adolescents, is in line with the findings of an interview study among 32 adolescents. In that study it was found that unclear responsibility complicated the adolescents' efforts to achieve autonomy. When the responsibility was unclear the parents needed to control the self-management, which could be seen as nagging, resulting in conflicts (Karlsson et al. 2008). If the responsibility is clarified, the parents know when they are in charge and should remind the adolescent. In an interview study, Wennick et al. (2009) showed that parents of youths with diabetes reported having ambivalent feelings about parenthood. Their responsibility had increased owing to the diabetes, but on the other hand they felt there was a need to hand over the responsibility to the adolescents. This indicates the need for parental education and support in constructive parental involvement.

The findings in Paper III showed that the distribution of responsibility could vary between adolescents and parents. Some days the parents felt they needed to take more responsibility and some days the adolescents could take more responsibility, especially if it meant more freedom, for example going to camp without the parents. In the interview study by Karlsson et al. (2008), the adolescents reported that more personal responsibility resulted in increased freedom. They also reported that they felt relieved when their par-

ents could take more responsibility when the self-management became burdensome.

However, psychosocial reasons (e.g. single-parent households) can make shared responsibility difficult. Hanberger et al. (2009) found that adolescents with separated parents reported lower perceived health and QoL than did those with parents living together. In a study among 2 062 adolescents from 19 countries, it was shown that adolescents whose parents were not living together had more unsatisfactory disease control. Other variables associated with decreased disease control were parental over-involvement and greater disagreement over the responsibility for self-management between adolescents and parents. The authors stressed the need for diabetes care teams to support adolescents and parents in managing the transition from parent-dominant to adolescent-dominant responsibility for diabetes self-management (Cameron et al. 2008).

A gradual transfer of the responsibility from the parents to the adolescent in a long-term, ongoing process appeared to be recommendable (Paper III). This is supported in a review of difficulties in diabetes management in adolescence (McConnell et al. 2001).

Methodological considerations

Paper I

Heinemann (2009) states that meal-related studies require attention to many aspects to be able to give meaningful results. This is also our experience from Paper I. Although attempts had been made to eliminate factors that could influence the results, the variability in post-prandial glucose levels was rather considerable. More preventive measures could have been taken: the infusion sets could have been changed every study day, the participants could have eaten a standardized breakfast at the clinic, and the blood glucose levels could have been clamped to a decided value before the study began.

The study had a small sample size. We might have found more differences if more participants had been included. However, the variability is extensive, but the mean and median levels are similar, between the different methods. According to the power calculation, the sample was large enough to detect a difference of 2 mmol/L in glucose levels, but not in AUC. Another question is that of reliability. The results could have been different with repeated measures.

Glucose values were followed for only three hours after the meal. A longer follow-up period may have given other results. But some hours after lunch, there is usually a need for an afternoon snack as recommended (NNR 2004), and then there is a need for another bolus.

The dual wave and the square wave were extended for only one hour in our study. A more prolonged bolus could also have given other results.

It can also be argued as to whether a greater difference between fat contents would have given different results.

Paper II

This study included 46% of the eligible adolescents using insulin pumps at the four clinics, which makes the external validity rather high.

It can be discussed whether a single day is sufficient to evaluate insulin omission. Adolescents have a habit of eating irregularly, and it is difficult to determine whether a bolus dose has been missed when you do not know a person's eating pattern. In a pilot study, we found that teenagers were able to remember what they had eaten the previous day but not before that, so we decided to use "the day before the visit" as the selected day of study. All bolus doses were accounted for, even those with snacks. The frequency of doses taken during the day of study correlated with the mean frequencies of doses for a period of four weeks, which indicated that the youths took bolus in a similar pattern each day.

Papers III and IV

The interviews were conducted by a diabetes nurse (the author of the thesis) with experience working with adolescents with diabetes. This may have limited the studies' credibility, as she may have been influenced by her own views on the problem. On the other hand, she had the ability to ask appropriate questions and understand the meaning of the answers. The two other members of the research team had no such experience, and as the interviews were consecutively analysed they could give advice and specify interview questions before every interview.

The transferability might have been decreased due to the ethnically homogenous sample, although we strived to include participants of different demographic backgrounds. The extent to which the findings can be transferred to other settings and cultures remains to be explored.

There is a need for a longitudinal study in which these findings are tested in an intervention to investigate whether they can decrease the frequency of insulin omission.

Conclusions and clinical implications

- In managing the glucose levels after a recommended main meal, no method of bolusing could be determined as superior.
Based on this study, no general recommendation can be given regarding the superior bolus dose method to use with a recommended main meal.
- Normoglycaemic post-prandial levels could be reached in nearly half of the measurements regardless of bolus dose method.
Diabetes care teams can encourage CSII-treated adolescents to individually test which bolus method gives the most normal post-prandial glucose levels.
- Insulin omission was common and devastating for the disease control.
It is important to download the pump data or look in the memory function to detect insulin omission to be able to give appropriate help.
- There is a need to clarify the responsibility for diabetes self-management, in continuous negotiation between adolescents and their parents, to avoid missed bolus doses.
Diabetes care teams can encourage and support continuous negotiation to clarify the responsibility between the adolescent and the parents.
- A practical tool to facilitate negotiations about the responsibility was created.
The tool may facilitate negotiations about the clarification of the responsibility.
- The main reason for insulin omission among CSII-treated adolescents is “Lost focus”.
This may help diabetes care teams understand the circumstances in which adolescents miss their bolus doses and may make it easier to discuss missed doses.
- Strategies for avoiding missed doses are agreements involving reminders.
Diabetes care teams can encourage and support these agreements.

- It is crucial that the adolescents be involved in these agreements; otherwise, the reminders can be seen as nagging and may not work.
Diabetes care teams can stress the importance of the adolescents' involvement.

Further research

There is a need to develop tools for educating and motivating adolescents using insulin pumps to perform sufficient diabetes self-management. One key tool may be parental involvement. There is a need for parental education in which parents are taught constructive parenthood and learn methods for clarification of the responsibility. The question is whether special parental education, based on the theoretical insight gained from this thesis and earlier studies, can decrease the frequency of missed doses and improve disease control. The aim of a future prospective, randomized, controlled study could be to investigate the outcome of special parental education in connection with the start of insulin pump treatment on the frequency of missed bolus doses and disease control.

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Summary in Swedish

Egenvård bland ungdomar som använder insulinpump

Antalet barn och ungdomar med typ 1 diabetes ökar i Sverige och andra länder. Typ 1 diabetes kräver behandling med insulin, som kan ges antingen med flera injektioner per dag eller med insulinpump. Barn och ungdomar med diabetes behandlas av speciella barndiabetesteam som finns på Sveriges 43 olika barnkliniker. Diabetesbehandlingen bygger på egenvård som barn, ungdomar och deras föräldrar utför. Ungdomar med diabetes kan ibland uppleva denna egenvård krävande. En viktig uppgift för diabetesteamen är att hitta metoder för att kunna stödja och samarbeta med ungdomar med diabetes och deras familjer.

Användningen av insulinpump ökar inom barndiabetesvården och används idag av cirka 30% av de 8000 barn och ungdomar som har diabetes i Sverige. Studier visar att det finns möjlighet till förbättrad blodsockerkontroll och livskvalitet med hjälp av insulinpumpbehandling. Många ungdomar har dock, trots insulinpumpbehandling, en otillfredsställande blodsockerkontroll, vilket ökar riskerna för diabeteskomplikationer.

Syftet med denna avhandling var att utforska aspekter på egenvården hos ungdomar med diabetes som använder insulinpump för att kunna beskriva förutsättningar som bidrar till den rekommenderade blodsockerkontrollen.

Vid insulinpumpbehandling injiceras en förprogrammerad basaldos kontinuerligt. Basaldosen består av cirka halva den totala dagliga insulin dosen, den andra delen består av bolusdoser (måltidsdoser), som ges till alla måltider och mellanmål. Bolusdoserna ges genom knapptryckning på pumpen. Det är möjligt att ge bolusdoserna på olika sätt, de kan ges på normalt sätt, då hela dosen injiceras på en gång. Bolusdosen kan också delas upp så att en del av dosen injiceras på en gång medan den andra delen injiceras under en längre tid, denna bolusdos kallas dubbel förlängd dos. Det finns också möjlighet att ge hela dosen under längre tid, så kallad förlängd dos. Tidigare studier har visat att dubbel förlängd dos är fördelaktigt att ge till en pizzamåltid. Inga studier har dock visat vilken dos som är bäst till en måltid sammansatt enligt livsmedelsverkets rekommendationer.

Syftet med studie I var att undersöka om något sätt att ge bolusdos, till två olika pastamåltider, var mer fördelaktigt för blodsockervärdena, och att jämföra blodsockervärdena med tonåringars utan diabetes. Den ena pastamåltiden var utformad enligt livsmedelsverkets rekommendationer, den andra

måltiden hade ett högre fettinnehåll. De olika bolusdoserna som prövades var normal dos, dubbel förlängd, och förlängd dos. Femton flickor med diabetes och 10 som inte hade diabetes ingick i studien. Flickorna var mellan 13 och 20 år. Blodsockervärdena följdes från 30 minuter före måltiden till 3 timmar efter.

Resultaten visade inte på några stora skillnader mellan de olika sätten att ge bolusdos. Till den rekommenderade måltiden gav den förlängda dosen en högre blodsockerstegring efter en timme. Efter den fetare måltiden var det inte några skillnader mellan de olika bolusdoserna. Flickorna utan diabetes hade en tidigare och lägre blodsockertopp och i genomsnitt lägre blodsockernivåer under hela mätperioden.

Hos flickorna med diabetes visade 48% av mätningarna normala blodsockernivåer efter måltiderna. De normala nivåerna fanns efter alla olika sorters bolusdoser. Patienter med insulinpump kan uppmuntras att individuellt testa vilken dos som ger de bästa blodsockervärdena.

En orsak till att ungdomar med insulinpumpbehandling har en otillfredsställande blodsockerkontroll kan vara att de inte tar bolusdoser till alla måltider. Tidigare studier från USA och Polen har visat att uteblivna måltidsdoser är vanligt och att ett ökat antal uteblivna doser ger en försämrad blodsockerkontroll.

I studie II undersökte vi hanteringen av insulinpumpar, inklusive administreringen av bolusdoser, hos ungdomar med typ 1 diabetes. Nittio ungdomar, i åldern 12-18 år, från fyra olika barndiabeteskliniker i Sverige inkluderades.

Resultatet visade att uteblivna bolusdoser var vanligt. Trettioåtta procent (n=34) hade missat minst 15% av doserna dagen innan undersökningen. Ett högre antal uteblivna doser medförde försämrad blodsockerkontroll. De som missade fler doser tog i genomsnitt färre bolusdoser och mätte färre blodsocker per dag. De hade också en högre andel basaldos i pumpen men samma totaldos som de som tog fler doser. Det fanns en trend, att de som missade mer, hade använt insulinpump under en längre tid. De upplevde ett större känslomässigt motstånd när de tog insulin och var mer störda av det i dagliga livet. De upplevde sig också mer styrda av diabetes och var tröttare på att mäta blodsocker. Alla ungdomarna upplevde stor behandlingstillfredsställelse med insulinpumpsbehandling, men de som missade mindre var mer tillfredsställda.

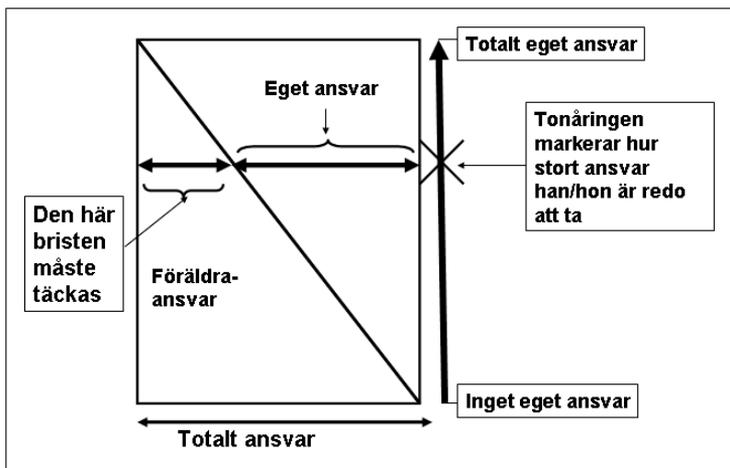
Det är viktigt för diabetesteamen att ladda ner pumpdata för att upptäcka om det saknas bolusdoser och i så fall kunna ge rätt stöd.

Orsakerna till uteblivna bolusdoser är tidigare inte så väl studerade. En studie rapporterar glömska som vanligaste orsaken. Andra orsaker som rapporteras är lågt blodsocker, svårigheter att ta fram pumpen och tidsbrist.

I studie III ville vi få förståelse och teoretisk kunskap om de processer som sker när ungdomar tar eller missar att ta bolusdoser. Studien var en intervjustudie där vi använde metoder baserade på "Grounded Theory" för att

samla in och analysera data. Tolv ungdomar, fem pojkar och sju flickor som använt insulinpump minst tre år intervjuades. De var mellan 12 och 19 år. Intervjuerna skrevs ned ordagrant och analyserades efterhand. Två huvudkategorier urskiljdes: ”ansvar” och ”tappat fokus”. Vi valde att analysera huvudkategorin ”ansvar” i studie III och vidare studera ”tappat fokus” i studie IV. Eftersom huvudkategorin i studie III var ansvar intervjuade vi även några föräldrar, som har det formella ansvaret. Tre mammor och en pappa intervjuades. För att skapa ytterligare kunskap intervjuades även en diabetessjuksköterska med lång erfarenhet av ungdomar med insulinpumpbehandling.

Utifrån insamlade data förstod vi att det fanns ett behov av att klargöra ansvarsfördelningen för egenvården, i ständiga förhandlingar, mellan ungdomarna och föräldrarna för att undvika uteblivna bolusdoser. Huvudkategorin var ”ansvar” och vi kunde urskilja tre underkategorier; ”fördelning av ansvar”, ”överföring av ansvar” och ”klargörande av ansvar”. Fördelningen av ansvar var klarare bland dem som inte missade så många doser. Antingen hade de ett stort eget ansvar eller också var ansvaret delat med föräldrarna. Bland dem som missade fler doser sågs en ansvarsbrist. Ansvarsfördelningen kunde variera. Vissa dagar kunde ungdomarna ta ett större ansvar, speciellt om det också medförde en större frihet, som att kunna åka på ett läger utan föräldrar. Det mest fördelaktiga var en gradvis ansvarsöverföring från föräldrarna till ungdomarna. Ansvarsfördelningen behövde klargöras i ständiga förhandlingar. En modell för att underlätta dessa förhandlingar skapades (Figur 7). Det är viktigt för diabetesteamet att stödja dessa förhandlingar och uppmuntra till ständiga omförhandlingar.



Figur 7. En modell för att underlätta förhandlingar och klargöra ansvarsfördelningen för egenvården mellan tonåringar och föräldrar. Rektangeln är delad i två delar: *Eget ansvar* och *föräldraansvar*. Tonåringen markerar hur stort ansvar han/hon är redo att ta. Därefter förhandlas om hur ansvarsbristen ska täckas och av vem.

I studie IV avsåg vi att undersöka orsaker till missade doser och strategier för att undvika dem. Vi använde samma analysmetoder som i studie III. När vi hade färdigställt studie III gick vi tillbaka till intervjudata från ungdomarna och fortsatte analysen efter huvudkategorin ”tappat fokus”.

Analyserna visade att huvudorsaken till missade bolusdoser var tappat fokus. Tre underkategorier identifierades; ”fördröjt tappat fokus”, ”direkt tappat fokus” och ”totalt tappat fokus”. Strategier för att undvika att missa doser var överenskommelser om påminnelser, dessa kunde vara personliga eller tekniska.

Med ”fördröjt tappat fokus” menas de situationer när ungdomarna avser att ta dosen efter måltiden, men då tappar fokus och glömmer den. En del ungdomar tog alltid dosen efter måltiden men de flesta gjorde det bara vid speciella tillfällen. Tillfällen då de kunde välja att ta dosen senare var vid låga blodsockervärden, om de var i sällskap där de kände sig generade att visa pumpen och om pumpen satt oåtkomlig under kläderna, t ex om de hade klänning. Vid ”direkt tappat fokus” tappas fokus på bolusdosen direkt i anslutning till starten av måltiden. Detta var vanligt om ungdomarna var i en stressig miljö, t.ex. skolmatsalen. Ungdomarna beskrev erfarenheter av ”totalt tappat fokus”, då diabetesbördan känns för tung, och de inte orkat med egenvården och bolusdoserna. Många höga blodsockervärden kunde bidra till totalt tappat fokus. En annan form av totalt tappat fokus var när ungdomarna ignorerade att de hade diabetes och försökte vara som alla andra.

Ungdomarna som tog de flesta bolusdoserna, tog dessa av vana, utan att alltid tänka på det. Det var lättare att komma ihåg om man tog direkt till maten i stället för att vänta till efter maten. Flera ungdomar behövde påminnelser för att ta doserna. De föredrog ofta personliga påminnelser, men det var viktigt att dessa påminnelser var överenskomna annars upplevdes de som tjat. En del hade erfarenhet av tekniska påminnelser som larm i pumpen, det kunde fungera under en kortare tid, men efter en tid ignorerades larmen lätt. Även de tekniska larmen behövde vara överenskomna. De som använt kontinuerlig blodsockermätning upplevde att det minskade antalet glömda doser och gjorde det lättare att upptäcka en missad dos tidigare.

Sammanfattningsvis har avhandlingen beskrivit olika förutsättningar för en bra blodsockerkontroll hos ungdomar som använder insulinpump. Det är möjligt att uppnå normala blodsockervärden med olika bolusdosmetoder och ungdomar bör uppmuntras att individuellt testa vilken dos som passar bäst till olika måltider. En klargjord ansvarsfördelning för egenvården av diabetes mellan föräldrar och ungdomar och vid behov överenskommelser om påminnelser kan bidra till en bra blodsockerkontroll. En ansvarsbrist för egenvården och tappat fokus kan orsaka uteblivna bolusdoser. Missade doser är vanligt och ger försämrade blodsockerkontroll.

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