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Education for Teenagers with Type 1 Diabetes

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Abstract

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Education for teenagers with diabetes has had limited effects to date, especially regarding metabolic control. The development had been towards more patient-centred approaches, like empowerment, motivational interviews and family behavioural programmes. A patient-centred approach means that the patient is expected to take control of the management of the disease. The empowerment approach has been implemented in adults with diabetes, with some positive results.

The aims of this thesis were to evaluate empowerment group education and education in a camp setting, and to validate the "Check your health" instrument which can be used to assess the effects of such education programmes on perceived health and the burden of diabetes.

Thirty-two teenagers between 12 and 17 years of age were randomized to either an intervention group or a wait-listed control group. The intervention consisted of six group sessions with an empowerment approach as the theoretical frame. Thirty-one of the teenagers were interviewed two weeks after the empowerment education programme was completed.

The programme did not have any positive effect on metabolic control between-groups, but within groups HbA1c and readiness to change increased. According to the definition of empowerment, which pinpoints decision-making, the interviews were analysed with that in focus. In the interviews the teenagers described five categories they perceived as important for decision-making competence: cognitive maturity, personal qualities, experience, social network and parent involvement. Parent involvement was described as both constructive and destructive. These categories were interpreted in the overall theme that "teenagers deserve respect and support for their shortcomings during the maturity process".

Ninety teenagers between 14 and 17 years of age attended education in a camp setting and were compared to a reference group, who had declined participation. The camp did not have any positive effect on metabolic control, but the frequency of insulin pump use after camp education increased. In a cross-sectional comparison, the campers had more positive attitudes towards diabetes and self-care than the non-campers did.

The "Check your health" instrument was tested for reliability and validity in 199 teenagers between 12 and 17 years of age. The instrument was found to be reliable and valid for use on a group level in teenagers with diabetes.

In conclusion, empowerment education programmes should be tailored to suit young people with diabetes, and should preferably be integrated into routine care. Teenagers who prefer individual education may be offered an individual education plan. Parents should be involved in all education of teenagers with diabetes, with the purpose of increasing teamwork and decreasing control and conflict. Continued assessment of teenagers perceived health and perceived burden of diabetes can be carried out using the "Check your health" instrument.

Keywords: Type 1 diabetes, empowerment, patient education, adolescence, camp, Quality of Life, health


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A consumer is the most important
visitor on our premises.
He is not depended on us.
He is not as interruption on our work.
He is the purpose of it.
He is not an outsider on our business.
He is apart of it.
We are not doing him a favour
by serving him.
He is doing as a favour by giving
us an opportunity to do so.

Mahatma Gandhi

Omslagsdesign av Jenny Dafgård

List of Papers

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

- I Viklund G, Örtqvist E, Wikblad K. Assessment of an empowerment education programme. A randomized study in teenagers with diabetes. *Diabetic Medicine*. 2007;24: 550-556.
- II Viklund G, Wikblad K. Teenagers' perception of factors affecting decision-making competence in the management of type 1 diabetes. (Submitted)
- III Viklund G, Rudberg S, Wikblad K. Teenagers with diabetes. Self-management education and training on a big schooner. *International Journal of Nursing Practice*. 2007;13:385-392.
- IV Viklund G, Wikblad K. Psychometric properties of the instrument "Check your health" – Measuring self-perceived health in teenagers with diabetes. (Submitted)

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

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Abbreviations

CSII	Continuous Subcutaneous Insulin Infusion
DCCT	Diabetes Control and Complication Trial
DCGM-37	DisabKids Chronic Generic Module-37
HbA1c	Glycosylated Haemoglobin A1c
HRQL	Health Related Quality of Life
ITT	Intention to Treat
ISPAD	International Society for Paediatric and Adolescent Diabetes
QoL	Quality of Life
RCT	Randomized Controlled Trial
SDD	Semantic Differential in Diabetes
Swe-DES-23	The Swedish Version of the Diabetes Empowerment Scale

Preface

The first time I realized that patient education may be ineffective was when, as a young nurse in primary health care for children, I met a mother and baby from Turkey. After giving her my recently learned food advice, it occurred to me that I had no idea what kind of food she kept in her refrigerator and that I had to start by asking her that. I realized that patient education that was not grounded in the patient's real life was not going to lead to the desired effects.

This was an important experience, and I try to keep it in mind while working as a clinical nurse specialist, educating children and teenagers and their families in diabetes management. Already in the late 80s, the diabetes team I have been working with began incorporating diabetes camps into the educational programme. The education model in these camps has changed from a class room education with a teacher, to education in smaller groups, but over the years the model has also developed more and more into patient-centred group education, which is grounded in my early experience of a patient-centred approach with the mother from Turkey.

It is easy to perceive the happiness the teenagers express, when meeting other young people in the same situation, and all members of the team are convinced that the camps have had positive effects on the teenagers.

This environment gradually raised my interest, in increasing the knowledge about and evidence of the success of patient-centred education for teenagers with diabetes.

Introduction

The overall purpose of diabetes patient education should be to make life easier for those with diabetes. An easier life may result in good quality of life, without severe acute adverse events and a lower risk of developing late diabetes complications. For supporting teenagers with diabetes in being their own experts, effective patient education has an important place in diabetes care (Hanås 2004, Swift 2007).

Diabetes and adolescence

Adolescence is a period in life when different hormones decrease insulin sensitivity, which leads to a demand for larger insulin doses and a risk of deteriorated metabolic control (Acerini *et al.* 2000, Acerini *et al.* 2001, Dunger *et al.* 2005). In addition to this, adolescence is a period when young people are to develop autonomy in the management of diabetes. The combination of both physical and psycho-social factors explains why adolescents quite often have to struggle to manage their disease.

A teenager with diabetes has to balance the intake of carbohydrates, physical activities, acute infections, stress, and the impact of other hormones with the amount of insulin injected. Imbalance in the glucose metabolism leads to blood glucose values being either above or below normal values. Metabolic regulation over time is measured as Glycosylated Haemoglobin A1c (HbA1c).

An insulin deficit may cause increased thirst, polyuria, tiredness, weight loss, stomach pain and vomiting, and if not diagnosed leads to ketoacidosis, an acute, severe complication to diabetes. If ketoacidosis is not treated properly it may lead to unconsciousness or even death (Dunger *et al.* 2004, Edge *et al.* 1999, Sartor & Dahlquist 1995).

Long-standing, high blood glucose (measured as HbA1c) is the most important risk factor for the development of serious micro- and macro-vascular complications like kidney damage, impaired vision or foot ulcers that may lead to leg amputation (Lachin *et al.* 2008). There are studies that confirm that good metabolic control can delay or prevent late complications as well as decelerate the progression of already existing complications (Dahl-Jørgensen *et al.* 1986, DCCT 1993, 1994, Reichard *et al.* 1993) (DCCT=Diabetes Control and Complication Trial). According to these re-

sults, the International Society for Paediatric and Adolescent Diabetes (ISPAD) have set the target for HbA1c at <7.5% (DCCT standard, 6.6% Swedish Mono-S) (Rewers *et al.* 2007).

Low blood-glucose values may lead to acute symptoms such as irritability, shaking, sweating, tachycardia, confusion, double vision and headache, and sometimes more severe symptoms or even unconsciousness and seizures. Lower global quality of life was reported in patients after severe hypoglycaemia (Nordfeldt & Jonsson 2001), but education may decrease the incidence of severe hypoglycaemia (Nordfeldt *et al.* 2005).

Transition is a concept that means a period between two stable states in a person's development. This period brings instability and vulnerability. One may see adolescence as a transition period between two stable states in life, namely being a child and being an adult (Lenz 2001). During this period there are different factors that facilitate or aggravate people reaching a subjective sense of wellbeing, mastery of new behaviours and wellbeing of relationships when the transition is completed (Schumacher & Meleis 1994).

One important issue for nurses may be to facilitate transition to enhance wellbeing, asserting that transition is a concept that should be seen as central in the nursing discipline. One study defined four different factors that influence transition: physical wellbeing, level of knowledge and skills, meanings and expectations (Meleis & Trangenstein 1994).

According to the transition perspective (Murphy 1990), adolescence is both a developmental-maturational transition, due to the "biological clock", and a role change from the status of parents taking responsibility to one of autonomy. If health care personnel view adolescence as a transition towards adulthood, it may make it possible to see the development towards a goal in a longer perspective. This perspective conceptualizes human response to changes and presents an opportunity to focus on factors facilitating development towards mature self-management in a longer perspective instead of immediate goal achievement. Parent support is important, but unclear divisions of responsibility in self-management between teenagers and parents may complicate the transition process (Karlsson *et al.* 2008).

Another author (Schlossberg 1981) discussed transition intervention strategies, suggesting that such interventions should include attention to clients' concerns, identification of themes, action and problem solving, teaching coping skills and structuring support. These strategies lie close to the empowerment philosophy, which is a core concept in this thesis.

Patient education

In 2007, a qualitative study, in which the authors studied 22 people who were considered by either their physician or themselves as experts in diabetes management was conducted (Paterson & Thorne 2000). The participants were 24-81 years old and their diabetes duration ranged from 15 to 41 years, which means that some were teenagers when they got diabetes. The study was implemented in three steps: First, the members audio taped their self-management decisions daily; second, they were interviewed; finally they attended focus groups. The results showed that the development towards expertise is both trajectory, with sequential phases, and age-related, determined by both developmental age and age at onset of disease. The development is described as a movement through four phases: passive compliance, naïve experimentation, rebellion and active control. The two middle phases were both motivated by the goal of taking control and led to negative health outcomes and fluctuating blood glucose levels. Those are seen as important steps towards expertise in decision-making instead of irritating and counter productive.

Patient education for teenagers with diabetes

The ISPAD Guidelines from 2007 confirm that education is necessary for success in diabetes self-management (Swift 2007). In a systematic review Murphy and co-workers (2006) compared their results from a review of studies published after 2001 with the results from a previous systematic review by Hampson et al. (2001). In this comparison it was found that the proportion of RCT studies had increased (from 40 to 54%) as well as the number of participants in the interventions (53.8 to 79.7). Half the studies had a theoretical base in both reviews.

The effect size on metabolic control and psychosocial factors was small in both reviews; it was greater on psychosocial outcomes (median 0.37 in Hampson's study and 0.38 in Murphy's) than on metabolic control (0.18 Hampson, 0.17 Murphy).

In the review by Hampson et al. (2001), the effect size of HbA1c was very heterogeneous, and varied in the different studies from -0.48 to 2.03. The studies that showed the most negative and the most positive effect sizes both aimed at improving teamwork between parents and their teenagers.

The intervention with the most negative effect size was a randomized study aiming at maintaining parent-adolescent teamwork without increasing diabetes-specific family conflicts (Anderson *et al.* 1999). The intervention lasted 12 months. Eighty-five families were randomized to one of three study groups (teamwork, attention to control and control). All groups had four routine visits during the study, with the teamwork and the attention to control groups also meeting a research assistant 20-30 minutes before or

after each visit. In the teamwork group the focus was on parent-adolescent teamwork, while the attention to control group provided didactic traditional education. A deterioration in HbA1c in the teamwork group was seen at the end of the intervention, whereas 12 months later there was no significant difference between the groups. The main conclusion was that parent involvement can be strengthened without increasing family conflict about diabetes.

In the study with the largest effect size on glycaemic control, 32 families were randomized to multifamily intervention (MF, n=11), MF plus parent simulation of diabetes (MF+S, n=12) or control group (n=9). Six months after intervention, the MF and the MF+S groups had significantly decreased their HbA1c (effect size 1.18 and 2.03) (Satin *et al.* 1989).

Since the beginning of the 20th century youths with diabetes have been offered participation in diabetes camps. Diabetes camps are often a combination of recreation and patient education. In a review, Norris *et al.* (2002) evaluated ten studies, measuring a variety of different outcomes. The most common measure was knowledge, but psychosocial factors and metabolic control were also evaluated. They concluded that there is insufficient evidence of the effectiveness of camps on any psychosocial variable, but that knowledge increased. In their review, Hampson *et al.* (2001) concluded that camps have shown different positive effects, such as increased knowledge, fewer self-reported behavioural problems, a significant increase in independence in insulin administration, an increase in reports of the intention to use more adaptive stress-management techniques and in self-perception of assertiveness, and a beneficial impact on metabolic control. However, they concluded that it is difficult to know whether these effects are due to the intervention or the experience of attending a camp.

New technologies, like mobile phones and computers, have created new options in patient education. There are Randomized Controlled Trials (RCT) that evaluate telephone support either through phone calls or text messaging (SMS). None of these studies showed improvements in HbA1c or psychosocial factors (Franklin *et al.* 2006, Howe *et al.* 2005, Howells *et al.* 2002, Lawson *et al.* 2005, Nunn *et al.* 2006), but some enhanced adherence to treatment (Franklin *et al.* 2006, Howe *et al.* 2005).

A comparison between group visits/computer-assisted consultation and regular out-patient consultations, no effect on HbA1c was found although the authors did find beneficial effects on Health Related Quality of Life (HRQL) in older teenagers (Graue *et al.* 2005a).

In a recent review of the previous review studies, the authors looked for commonalities in the different educational approaches that influenced the effectiveness of an educational programme. Their conclusion was that educational programmes should be theoretically grounded and tailored to be diabetes-specific. Interventions such as coping skills training and family-focused teamwork are important, and flexibility is required. The intervention

setting and method of delivery should meet the needs of the participants and the mechanisms for sustainability, and should also consider socio-cultural factors of the population being served (Hood & Nansel 2007).

Murphy et al. (2006) concluded that routine care is not enough for obtaining ISPAD's goals for metabolic control. Further, they claimed that educational programmes are most effective when integrated into routine care, when parent involvement is encouraged and when teenagers' self-efficacy is promoted.

According to the review by Hampson et al. (2001), no study has compared the benefits of individual vs. group interventions.

Empowerment

Psychotherapist Carl Rodgers and pedagogue Paolo Freire are two representatives of a tradition that embraces people's inner capacity for change towards a better life, and they believe that this capacity is social and constructive. The environment can create a climate that supports positive changes.

In his book *On Becoming a Person* (Rodgers 1961) the author has described the kind of relationship between a therapist and client that may help a person find his/her own capacity and use it for personal growth and development. To be able to compare this with a caregiver/patient situation, the first thing Rodgers mentions is that the caregiver has to be empathic and must communicate this to the patient. Secondly, the caregiver has to be aware of his/her own feelings and attitudes, and must show non-judgemental acceptance of the patient. Finally, the caregiver should be congruent and genuine in his/her relationship with the patient. According to Rodgers, moral or diagnostic evaluation is always threatening to the patient. The caregiver should meet the adolescent patient as a person in the process of *becoming*, which is a developmental approach, instead of *being*, which is a static approach. Rodgers asserts that this helps the patient find and use his/her potentialities; this is also in accordance with transition theory. In conclusion, Rodgers claims that individuals have an inner striving to develop, and that this striving is constructive and social. This tendency to develop is influenced negatively or positively by individual conditions, and if we as caregivers support it we might increase wellbeing, health and Quality of Life (QoL) in our patients.

The empowerment approach has its roots in Brazil, where pedagogue and philosopher Paolo Freire taught slum dwellers and peasants to read. In 1970 he described his educational philosophy in the book *Pedagogy of the Oppressed* (Freire 1996) where he expressed that people who are deprived of their voices are also deprived of their freedom. He wanted people to be liberated through education and take control over their lives. Freire also talked about people as "becoming" instead of "being".

Education should be based on reflection, problem-posing and dialogue. A deep consciousness helps people be aware of their situation, and this consciousness makes them susceptible to change. The content of education must be founded in reality, and in the educators' and participants' perceptions of reality. Grounded in reality, themes should be created, and these themes should form the foundation of the programme content. The pedagogy is further based on dialogue, which requires critical thinking. According to Freire, critical thinking is a prerequisite for communication, and communication is necessary for true education. A dialogue becomes real when it is built on humility, while self-sufficiency is counterproductive to true dialogue. The last step in empowerment education is that strategies and goals are put forward by the participants and lead to action.

Empowerment in diabetes education

Empowerment is built on Freire's philosophy, and is a patient-centred approach that has been practiced in diabetes education since the beginning of 1990s (Funnell *et al.* 1991). The group that started with empowerment education of adult patients with diabetes is situated in Michigan, USA. They have described "The Art of Empowerment" in diabetes education through patient stories and by proposing strategies for diabetes educators (Anderson & Funnell 2000). In a randomized controlled study, the group showed positive effects on 4/8 self-efficacy factors and on attitudes six weeks after an empowerment educational programme. Metabolic control was measured six weeks after intervention, and showed a significantly greater decrease in the intervention group compared to the control group (Anderson *et al.* 1995).

The definition of empowerment used by the Michigan group is: "People are empowered when they have sufficient knowledge to make rational decisions, sufficient control and resources to implement their decisions and sufficient experience to evaluate the effectiveness of those choices", (Funnell *et al.* 1991) (p 38). The group also listed the concepts of importance in diabetes education:

- Emphasize the whole person
- Emphasize personal strengths rather than deficits
- Let patient select learning needs
- Share and negotiate goals
- Transfer leadership and decision-making
- Emphasize self-generation of problems and solutions

A study of 88 mothers and their children (12-17 years old) showed that mothers' sense of empowerment had an influence on their children's adherence to treatment. The mothers' sense of empowerment and education also explained the variance in their children's metabolic control (Florian & Elad 1998).

Empowerment education for teenagers

A WHO report that reviewed the evidence of the effectiveness of empowerment education in improving health in teenagers showed positive effects on disease management, use of health services and mental health, as well as significant improvements in health and QoL in chronically ill patients. Components that were seen in programmes for young people were: viewing youth as a resource, engaging youths in group bonding through dialogue, and involving youths as decision-makers in their social actions. These components have shown a range of outcomes, such as self-strengthening, collective efficacy, stronger group bonding, and formation of sustainable groups, which increased their participation in social action and policy changes (Wallerstein 2006).

The definition of empowerment by the Michigan group puts a great deal of attention on making, implementing and evaluating decisions (Funnell *et al.* 1991).

Living with diabetes means having to make important decisions several times every day. The following story, constructed by the author during the analysis of interviews concerning factors affecting decision-making competence in the management of type 1 diabetes (presented in Paper II), is one example of what a couple of hours can be like for a teenager with diabetes:

“It started already on Monday morning, when I overslept, and knew that I had an important exam in my first class at school. I had no time to check my blood glucose value, and had to guess the insulin dose before breakfast. I couldn't skip my injection, because then I would have to go to the toilet during the exam. Arriving at school, I realized I had forgotten my glucose tablets, and I had to either take a chance or go find some fruit. I chose the latter. At lunch I was sitting with some people I don't know, and I didn't want them to know I have diabetes. I decided to take my injection after lunch instead of before. That's less optimal, but still better than skipping the injection.”

One study found a relationship between decision-making competence and adherence to diabetes treatment in adolescents, and discussed whether decision-making in relation to diabetes management is handled differently than it is in relation to other issues. (Miller & Drotar 2007) In another study, the same authors found that when mothers and adolescents perceived decision-making autonomy differently, the mothers reported an increase in diabetes-

related conflicts (Miller & Drotar 2003), which may show that parents play an important role in their teenagers' ability to make mature decisions.

In a review by Mårtenson & Fägersköld (2007), the authors stated that even if young people have lack of competence in decision-making, they should not be excluded from the human right to explore their will. The authors concluded that parents' and health-care professionals' attitudes were more important to children's decision-making competence in health care than was the child's own capacity.

Jolly and co-workers (2007) presented a model, based on Freire's philosophy, of how to use an adolescent's voice as a guide for nursing practice and research. The model consisted of storytelling, in which adolescents are given the possibility to present their own health story to a person that does not judge them, is an active listener and gives and gets feedback. The authors presented their model as an aid for improving health care for teenagers and as a foundation for further research.

Factors of importance for successful education in teenagers

Attendance Rate

If an education programme for teenagers with diabetes is to be successful, it has to reach as many people as possible. Attendance rates in educational programmes may be difficult to assess, because many studies do not report the eligible population before the exclusion process. Today, RCT studies should be presented with a flow chart (consort), which allows the reader to follow the inclusion in all steps (www.consort-statement.org). In a study with motivational interviewing, 39% of eligible patients were randomized, 31% continued treatment at six months, and 28% had complete data at the end of the study (Channon *et al.* 2007). Wysocki *et al.* (2008) randomized 18%, while 16% had complete data. The conclusion is that we do not know whether the other 72 and 84% were interested to participate in such programmes, if they do not want education at all, or whether they want other kinds of educational programmes.

No studies have been found that assessed individual factors influencing young people's willingness to attend diabetes educational programmes.

Behavioural interventions with or without parent involvement

Behavioural family systems therapy (BFST) were evaluated in a RCT with adolescents with diabetes (Wysocki *et al.* 2000). The programme had four

components: problem-solving training, communication training, cognitive restructuring and functional-structured family therapy. The study, which persisted for 12 months, showed improvements in parent-adolescent communication skills and parent-adolescent relations at the end of the intervention. They found no effect on metabolic control or treatment adherence.

The group revised the educational model with diabetes-specific behavioural components, and conducted a new randomized trial to assess whether the addition of diabetes-specific components to the programme would make it more efficient. In this study, they randomized 104 families to either the intervention group (BFST-D), an educational support group (ES) that received standard care plus 12 multifamily sessions within six months, or to standard care (SC). SC was the routine care practiced at each clinic, with quarterly visits. The study showed that besides improving family conflict and treatment adherence, HbA1c significantly decreased in both the BFST-D and the ES groups, especially in those with poor metabolic control. In a recent evaluation with long-term follow-up, HbA1c was still lower 12 and 18 months after intervention, and correlated significantly to adherence to treatment changes (Wysocki *et al.* 2007).

Another group in the US has tried motivational interviewing as an educational approach, and conducted an RCT on 66 teenagers (14-17 years of age) with diabetes (Channon *et al.* 2007). This method is patient-driven, and has a great deal in common with empowerment programmes, which have been found to be effective in adult diabetic patients (Anderson *et al.* 1995). The purpose of motivational interviewing is to increase the awareness of individual cost-benefit effects of making changes, consider different alternatives to current behaviour, problem solving, making choices, setting goals and avoiding confrontation. The conclusion from this study was that HbA1c decreased significantly in the intervention group, and was maintained for 24 months. There were also significant improvements in psychosocial variables in the intervention group, such as positive wellbeing, quality of life and differences in personal models of illness, and some of these improvements were still being maintained 24 months later (Channon *et al.* 2007).

Parent involvement

Adolescence is a period in life during which young people should gradually become mature and take over the responsibility for their diabetes management and coping strategies from their parents. There is a great deal of support in the literature for parent involvement in diabetes management being encouraged during adolescence (Wysocki & Greco 2006).

In an integrative review study, Dashiff *et al.* (2008) have tried to synthesize findings on interaction and communication between adolescents with diabetes and their parents. They addressed six significant concepts: support, control, conflicts, involvement, emotional qualities of communication and

congruence of perspectives. They found that the most common outcome measure was HbA1c, but adherence and quality of life had also been measured in some studies. Parent support was described as understanding the demands of diabetes, proposing solutions and asking questions to gain understanding, and was positively associated with both metabolic control and adherence. Parent control and parent-adolescent conflicts were negatively related to quality of life, diabetes-related satisfaction and metabolic control. Differences in perceptions led to conflict and were related to poorer metabolic control.

Parents of young children (8-12 years) were more involved in diabetes management than were those of older children (13-17 years), and the involvement of parents was a predictor of adherence to blood glucose monitoring in both age groups (Anderson *et al.* 2002).

Hanna *et al.* (2003) suggested that health care personnel should encourage parents to support their teenagers through middle adolescence (14-16 years), but they also argued that receiving parent support that is not needed or wanted may hinder an adolescent's development into a mature decision maker. Teenagers with diabetes reported a higher degree of parent control than did healthy adolescents as well as adolescents with other disabling diseases, and the authors discussed the possibility that teenagers who are pushed too hard towards autonomy and responsibility risk having management problems (Graue *et al.* 2005b).

The relationship between parents and teenagers should be considered a central component of health care delivery, and should be assessed regularly by clinicians (Leonard *et al.* 2005). It seems clear that proper parent involvement is important during adolescence, but the way this transfer of responsibilities for diabetes management from parent to child during adolescence should be carried out is not clearly elucidated.

Evaluation of patient education

Metabolic control, measured as HbA1c, is probably the most common outcome assessed in patient education. Other outcomes measured may be for example attitudes, empowerment factors, behavioural change and burden of diabetes.

Several different concepts regarding the evaluation of patient education are used in the literature, for example: Quality of Life (QoL), Health Related Quality of Life (HRQL), perceived health, functioning and psychological outcomes (Dantzer *et al.* 2003, Delamater 2007, Muldoon *et al.* 1998, Murphy *et al.* 2006, Varni *et al.* 2007). This thesis focuses on perceived health and QoL.

In a meta-analysis of 12 studies that evaluated the difference between the two constructs QoL and perceived health, the strongest correlations were

found between the two constructs. Mental health had the strongest correlation to QoL, and physical health to perceived health. Although the two constructs had strong correlations with each other, the authors drew the conclusion that QoL and perceived health are distinct constructs (Smith *et al.* 1999).

A comparison of these results with those from a similar study on adolescents showed that the constructs of QoL and “self-rated” (perceived) health are not interchangeable for teenagers. Both mental health and physical health were more strongly correlated to QoL than to perceived health. Mental health appeared to make a greater contribution to perceived health than did physical health, which is different compared to adults. Low correlations were found between social functioning and both QoL and perceived health, and may have overlapped with mental health, which is important to consider when measuring QoL in teenagers. The authors also discussed whether other possible domains should be rated when adolescents self-rate QoL and health (Zullig *et al.* 2005).

In a debate in British Medical Journal about what QoL actually measures, it was concluded that QoL-studies have looked for two different kinds of information, the individuals’ functional status (objective functioning) and perceived health (subjective wellbeing) (Muldoon *et al.* 1998).

Health-related quality of life

HRQL is a construct that is very often used in the literature, but it is seldom defined (Cameron *et al.* 2007, DeWit *et al.* 2007, Varni *et al.* 2007). It is often used as if it were interchangeable with QoL; for example, in the title of the handbook on the DiasabKids Chronic Generic Module-37 (DCGM-37) the authors use QoL, while talking about HRQL in the text (Bullinger & Group 2006). In another study the authors claimed that because QoL is a holistic concept, it is difficult to determine the extent to which a chronic disease may have influence on general QoL, and based on this they do not recommend the use of HRQL, but rather a distinction between QoL and disease impact on perceived health (Wallander *et al.* 2001).

Health

It is important to define health, because we want all projects and activities with good health as a goal to have a reasonable orientation. It is also important to be able to compare health between people as well as in the same person at different periods of time.

In 1947, the World Health Organization defined health as a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity. They reaffirmed this in the Alma-Ata declaration 1978, stating that health is a fundamental human right and the attainment of the

highest possible level of health is the most important world-wide social goal (WHO 1978).

Two different theories are discussed by Nordenfelt (1991): One theory, presented by Christoffer Boores in 1977, claims that a person who does not have any disease is healthy. Boores distinguishes between disease (theoretical) and illness (clinical), and states that biological functions are measurable, and that it is possible to define what is normal and abnormal. According to his theory a lack of functions leads to poor health (Nordenfelt 1991). This health theory may be compared with “health as clinical status” (Brülde & Tengland 2003).

Nordenfelt (1991) further described health from a holistic perspective. In an interpretation of Nordenfelt’s health theory, it is seen as the capacity to fill one’s basic needs, fulfil one’s wishes and to realize vital goals. It is to be able to do things others can do, to do things one usually does, but is also a function of basic capacities and the extent to which these capacities can be used. According to Nordenfelt, it is necessary to correlate capacity and individual goals to make this theory reasonable.

The health definition by Pörn says that having good health means being able to achieve or realize your wishes under certain circumstances. This theory is based on a balance between the actual environmental circumstances and a person’s goals (Brülde & Tengland 2003).

Nordenfelt (1991) also distinguished between subjective health (when a person feels or believes that he/she is healthy) and objective health (when the person has no disease). Subjective health, defined by Nordenfelt, may be compared to “manifest health”, which means how well or ill a person feels and functions at a certain occasion (Brülde & Tengland 2003), and perceived health (Smith *et al.* 1999, Zullig *et al.* 2005). A person may be objectively healthy but have poor subjective health, or he/she may have poor objective health but feels subjectively healthy.

A group from Wisconsin conducted a longitudinal study on risk factors for self-rated health in diabetic people less than 30 years of age, and found that sex and socioeconomic level had the most significant effect on health. They also found that younger age at diagnosis, less hospitalization and good glycaemic control predicted good health. Self-rated health decreased when diabetes duration increased in the group with onset between the ages of five and 20 years. Parents tended to report better health than did the person with diabetes (Huang *et al.* 2003).

The results from the study by Smith *et al.* (1999) showed that physical functioning was rated as the most important domain for perceived health, while mental health was considered less important for perceived health than it was for QoL. This was not in accordance with the results from the study on adolescents (Zullig *et al.* 2005), in which mental health was more important for health than physical health was. Social functioning had little impact on perceived health in adults (Smith *et al.* 1999).

It is possible to have good quality of life although one's health is decreasing, and good health is not enough to obtain good QoL.

Quality of Life

In his book, Nordenfelt (1991) described different theories of QoL. The Greek philosopher Aristotle defined the optimal good life (happiness) as a form of activity, but also made a distinction between happiness and prerequisites for gaining happiness. The last assumption is relevant to the discussion of happiness or QoL today, and leads to the conclusion that we have to consider an individual's personal qualifications to reach optimal happiness or QoL. Nordenfelt talks about welfare and wellbeing, whereby internal welfare, external welfare and a person's activity are prerequisites for optimal wellbeing. It is important to denote, however, that welfare can be different for different people, and should promote a person's wellbeing.

Jeremy Bentham (1748-1832) presented his theory of pleasure and pain, and was the one who laid the base for QoL-measure when he introduced the "Felicity Calculus" (Nordenfelt 1991).

Bentham's theory is consistent with hedonism, which can be summarized in the concept that only pleasant and unpleasant perceptions can have final significance on QoL. The degree of the experience is of importance for QoL, and a person's QoL at a certain point in time is only dependent on how the person feels at that time (Brülde 2003). This theory may cause limitations concerning the value of QoL measurements in care settings, while the result of the measure will only be valid in a short-term perspective.

For practical reasons we need to measure QoL on different occasions, but considering the complicated and different definitions of QoL one may wonder if this is possible. According to Brülde (2003), it is not possible to measure QoL properly regardless of which theory we use, even if the author concludes that we have to do so to be able to assess different interventions that have good QoL as a goal.

Wallander et al. (2001) made a clear distinction between QoL and the impact of disease on daily life, concluding that QoL is such a multi-component construct that it should not be confused with other constructs. They recommend the use of generic QoL instruments, possibly complemented by disease specific measures.

Again, it is possible to have good quality of life although one's health is getting worse, and good health is not enough to obtain good quality of life.

QoL and psychological health in teenagers with diabetes

As mentioned above, HRQL is often used interchangeably with QoL. The concepts reported in the following studies are those used by the authors.

Teenagers with ten different chronic diseases were compared with healthy controls regarding HRQL using the Pediatric Quality of Life Inventory (PedsQL), a generic instrument. The ten conditions compared were diabetes, gastro-intestinal conditions, cardiac conditions, asthma, obesity, end-stage renal disease, psychiatric disorders, cancer, rheumatologic conditions and cerebral palsy, and the patients in the diabetes group reported the highest overall HRQL. However, all scores in the diabetes group were lower than those of the healthy control group, except in the “social functioning” domain (Varni *et al.* 2007). These results are in accordance with Graue *et al.* (2003), who found that diabetic adolescents reported a lower degree of general health than did healthy adolescents while Wagner *et al.* (2005), on the other hand, found that teenagers with type 1 diabetes had HRQL equal to that of healthy controls.

Another area that is studied is the impact of diabetes on teenagers’ mental functioning. In a review, Dantzer and co-workers (2003) concluded that there is an association between anxiety/depression and diabetes in young people. This is supported by two later studies, which found that psychiatric morbidity was twice as frequent among teenagers with type 1 diabetes than among teenagers in general (Hood *et al.* 2006, Northam *et al.* 2005). An association was found between diabetes-specific burden/diabetes-specific family conflicts and decreased emotional functioning in the youths (Hood *et al.* 2006), and that the probability of depression increases when glycaemic control deteriorates (Hassan *et al.* 2006).

Relation between HbA1c and QoL

Several studies have tried to clarify the correlation between metabolic control and quality of life in teenagers with diabetes, and it seems that there is support for the hypothesis that there is a correlation, but the causality is not known. In a German study from 1998, a correlation between one-year mean HbA1c and QoL was found in adolescents (Mean age boys 15.1 ± 3.0 ; Girls 15.0 ± 2.5) and the authors found the same correlation, but weaker, between a single HbA1c and QoL (Guttman-Bauman *et al.* 1998). The Hvidøre Study group (Hoey *et al.* 2001) found that good metabolic control was associated with better QoL in 2101 adolescents from different countries, aged 10-18 years with type 1 diabetes. Two studies reported that good metabolic control correlated to better QoL, (Wagner *et al.* 2005, Vanelli *et al.* 2003), while a group from Norway who studied 115 teenagers between 11 and 18 years old were not able to confirm this correlation (Graue *et al.* 2005b).

In their consensus guidelines 2007, the International Society for Paediatric and Adolescent Diabetes (ISPAD) highlights the importance of regular assessment of both medical factors as well as of QoL in young people with diabetes (Delamater 2007, Rewers *et al.* 2007).

Different measures of QoL used in the literature

The 2007 Consensus Guidelines from International Society for Paediatric and Adolescent Diabetes (ISPAD) recommend that “assessment of developmental progress in all domains of quality of life (physical, intellectual, academic, emotional and social) should be conducted on a routine basis” (Delamater 2007) (p 343), while another group argued that mental health screening should be regarded as having the same importance or as having precedence over other complication screenings (Cameron *et al.* 2007).

In their review, Murphy *et al.* (2006) concluded that 40 different measures had been used to evaluate psychological outcomes, and only five had been used more than once. This makes comparisons of psychological outcomes between studies difficult, and although several measures are available, health, HRQL or QoL is seldom measured in clinical settings or clinical trials.

Muldoon *et al.* (1998) discussed problems with measuring QoL, and how to address them. They first pointed out the importance of describing whether objective measures (such as level of functioning) or subjective measures (such as perceived health) are used. Precision and clear descriptions are needed. Secondly instrument validity must be reported. Accuracy in reporting, influence of personal characteristics, change over time and external factors are other confounders when measuring QoL.

In a review, De Witt and colleagues (2007) discussed the advantages and disadvantages of generic and disease-specific measures. Generic instruments compare QoL or perceived health within a healthy population, while the disease-specific measures are more sensitive to clinical changes. Both generic and disease-specific instruments were evaluated with regard to reliability, validity, time to complete, recall period, parent report, norm scores, available languages and whether disease modules are available. In another review it was found that QoL is seldom measured in paediatric clinical trials. This could be due to the purpose of the trials, which often aim at assessing the effect of treatment on medical factors, and the authors argue that QoL measures are not always appropriate in this kind of study (Clarke & Eiser 2004).

It also seems as if the mode of administration, for example self- or interviewer administration, telephone administration, season or measure context, has an impact on the results of the measure (Hanmer *et al.* 2007).

Although several measures are accessible, QoL or perceived health is seldom measured regularly in teenagers with diabetes. There is still need for a

short, accessible measure that is easy to administrate on a regular basis in a clinical setting, and that is suitable for young people. The “Check your health” instrument is constructed as a thermometer, with only four scales: perceived physical and mental health, perceived social relations and overall QoL. The instrument also measures the person’s imagined physical and mental health, social relations and QoL, if he/she did not have diabetes, and because of this construct the instrument also allows evaluation of the perceived “burden of diabetes”. The instrument have been found to be valid and reliable for adults with diabetes (Wikblad *et al.* 2003).

Rationale of the thesis

Patient education for teenagers with type 1 diabetes is organized in different ways. It can be based on individual education, group education incorporated either within routine care or outside the hospital setting, diabetes camps, and with or without the involvement of parents. Different educational programmes for teenagers with diabetes have shown low to moderate effects on both metabolic control and psychosocial variables, and no special programme has shown evidence of being the most effective (Hampson *et al.* 2001b, Murphy *et al.* 2006).

Since the beginning of the 80s I have been working with diabetes education in different camp settings, together with a diabetes team. Over the years the education approach has developed towards more patient-centred group discussions, and I have become interested in the empowerment approach.

The empowerment approach has been used in diabetes education for adults with diabetes and has shown positive results, albeit in short-term evaluations (Anderson *et al.* 1995, Wikblad *et al.* 2004), and there was limited knowledge of the effect of empowerment education in teenagers with diabetes.

For this reason, teenagers between 12 and 17 years of age were asked to participate in an empowerment education programme, with six weekly group sessions. Of 55 randomized people, 32 completed at least four of six sessions, and were included in the analysis.

Empowerment in diabetes education was introduced at the beginning of the 90s (Funnell *et al.* 1991). The goal of empowerment was to support participants towards mature decision-making. According to previous studies, teenagers may have shortcomings in this field (Byrnes 2002, Mann *et al.* 1989); thus interviews, conducted two weeks after the empowerment programme, were analysed, aiming to elucidate factors of importance for decision-making competence.

The diabetes team to which I belong had noticed that the attendance rate at the diabetes camps we had been arranging for several years was low, and the question was raised as to whether the participants in some way differed from non-participants. The literature reported attendance rates between 7 and 30% (Channon *et al.* 2007, Schlundt *et al.* 1999), but knowledge of factors affecting participation was not found.

Against this background, six camps, held on a large schooner between 1998 and 2001, were evaluated regarding attendance rate and factors of im-

portance for camp participation. Effect on HbA1c and choice of treatment were also determined.

There are problems involved in comparing the effects of different educational programmes, because diverse outcomes are measured and many different measures are used (Murphy *et al.* 2006). Regular assessment of health and QoL in teenagers with diabetes is strongly recommended (Cameron *et al.* 2007, Delamater 2007) but seldom carried out. This may be due to the lack of a short, simple and valid instrument for use in a clinical setting. “Check your health” is an instrument that measures perceived health and perceived burden of diabetes. It has been found reliable and valid in adults with diabetes (Wikblad *et al.* 2003), but needed to be tested in teenagers.

Specific aims

To determine the effects of an empowerment programme on glycaemic control and empowerment (Paper I)

To study the role of parent involvement in empowerment group education (Paper I)

To explore teenagers' perceptions of factors affecting decision-making competence in diabetes management (Paper II)

To evaluate whether diabetic teenagers participating in a group educational programme (the schooner programme) differ from non-participants in attitudes towards diabetes and self-care (Paper III)

To evaluate the effects of the schooner programme on metabolic control and treatment (Paper III)

To evaluate attendance rate in two different education programmes (Paper III)

To test the "Check your health" instrument for reliability and validity in teenagers with diabetes (Paper IV)

Methods

Designs

Both quantitative and qualitative designs have been used in this thesis. The designs of the different studies are described in Table 1.

Table 1. Designs of the studies in the thesis.

Study	Design
The empowerment programme (I)	Randomized, controlled intervention study
Decision-making competence (II)	Qualitative, descriptive, explorative interview study
The schooner programme (III)	Cross-sectional comparative study
“Check your health” (IV)	Psychometric instrument testing

A wait-listed design was used in Paper II, which means that the control group received the same intervention six months after the intervention group.

Samples

Three different samples, a, b and c, were included in the thesis.

- A. In the empowerment intervention (I), 284 patients at an outpatient diabetes clinic were eligible for the study. Seven patients were excluded due to neuropsychiatric disorders or language problems, and consequently 277 were informed of the study. Figure 1 describes the sample and drop-outs in Paper I.

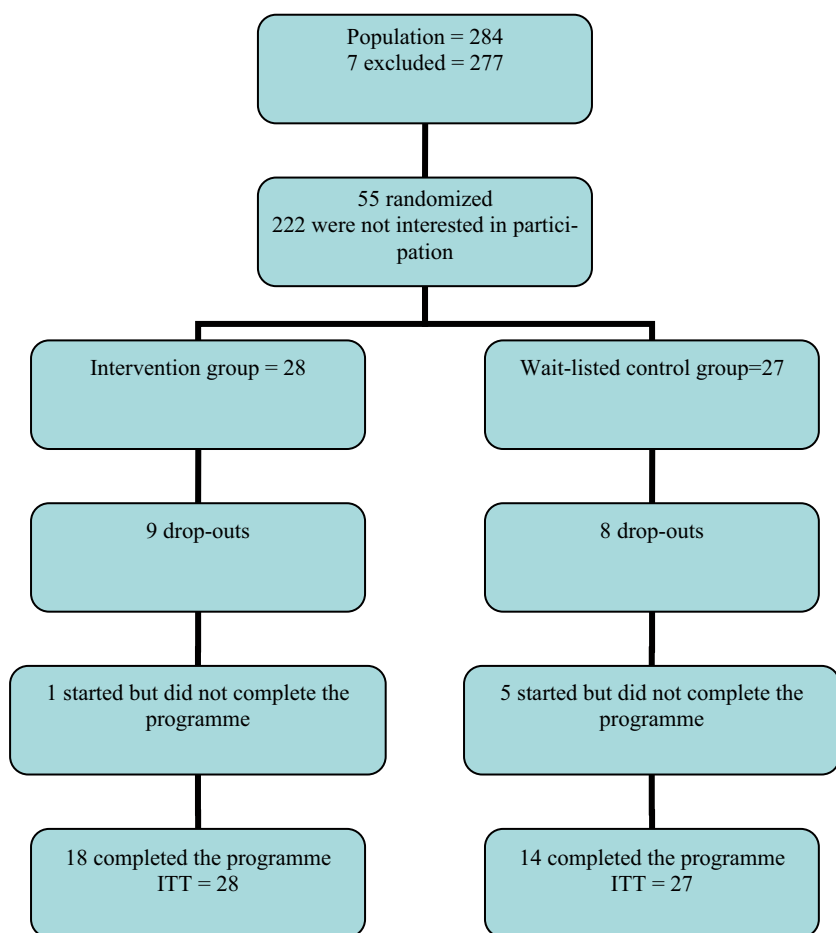


Figure 1. Description of the participants and dropouts in Paper I.

Completion of the programme was defined as attendance of at least four of the six meetings. A description of the group that fulfilled the programme, the Intention to Treat (ITT) group and the population at the clinic where the study was implemented is shown in Table 2.

Table 2. Baseline data for the patients who completed the programme, the Intention to Treat (ITT) group and the clinic population.

	Patients who completed the programme (n=32)	Intention to Treat group (n=55)	Clinic population (n=209) *
Age (years)	14.2 (SD=1.1)	14.2 (SD=1.3)	15.3 (SD=1.5) **
Duration of diabetes (years)	6.8 (SD=4.2)	6.6 (SD=3.9)	6.1 (SD=3.5)
HbA1c %	7.9 (SD=1.3)	8.0 (SD=1.5)	8.0 (SD=1.4)

*Data on 13 missing, **p<0.0001.

The sample from the empowerment group (A) was used in the interview study.

Thirty-eight people started the empowerment programme (I). Three dropped out of the programme at an early stage and 35 were asked to take part in the interview study (II). Three terminated participation and one interview was mistakenly not tape-recorded, and thus interviews with 17 girls and 14 boys were analysed. The mean age of the respondents was 14.2 years (Range 12-17) and the mean duration of diabetes was 6.8 years (range 1-15).

- B. In the schooner programme (III), 290 people were approached to attend camp. Ninety (48 boys and 42 girls, 14-17 years) chose to attend. Mean age was 15.5 years (SD=0.9), duration of diabetes 6.1 years (SD=3.8) and mean HbA1c 7.5% (SD=1.3). For comparison, an age and sex-matched reference group of 90 non-participants was recruited from the same clinic (mean age 15.6 years [SD= 1.2]; mean diabetes duration 6.5 years [SD=4.0] and mean HbA1c 7.6% [SD=1.6]).
- C. A convenience sample of 204 patients between 12 and 17 years of age was recruited from four diabetes centres to test the "Check your health" instrument (IV). Five people were excluded due to short diabetes duration. Forty-seven of these 199 patients completed the questionnaires at home a second time. Mean age was 14.7 years (SD=1.6) and mean duration of diabetes 6.3 years (SD=3.5). Mean HbA1c was 7.5%, and 20% of the patients were on Continuous Subcutaneous Insulin Infusion (CSII).

Interventions

The empowerment programme

The empowerment education programme (I) consisted of six weekly, two hour group meetings. All groups were also given the opportunity to invite their parents to an extra session at the end of the intervention. The purpose was to discuss what the group members had talked about during the previous six meetings. The group size varied from four to nine members between 12 and 17 years old. Each meeting had a predetermined theme, grounded in the empowerment approach:

- Life satisfaction and goal setting
- Problem solving
- Coping with emotions
- Coping with daily stress
- Social support
- Motivation

These themes were the starting point for the discussions and the goal of the education programme was to increase awareness of these issues and to improve the teenagers' competence to manage them in their daily life with diabetes. The method for the programme was Problem-Based Learning, which is previously described (Wikblad *et al.* 2004), and the approach was empowerment. Every meeting started with a take-off point to start the group members' reflections on the topic. Thereafter, a mind-map of everything that came to the teenagers' minds was produced, and problems were posed based on this. Literature and the Internet were used to gain knowledge, and the aim was to discuss new findings at the end of each meeting or at the following meeting. The last step was to find a way to use this knowledge in managing diabetes.

Before the first meeting a contract of rules was signed. The sessions were led by a diabetes nurse from the clinic, who was also the study researcher.

The schooner programme

The schooner programme (III) took place on a large schooner, and lasted for three days. The programme consisted of elective activities, social activities run by the crew and diabetes group discussions four to five hours daily. The groups consisted of five to six group members and were led by members of the diabetes team. Topics were suggested, for example alcohol and diabetes, food choices and pregnancy and diabetes, but the group also brought up problems they wanted to discuss. Structured blood glucose monitoring, and food experiments were also conducted.

Measures

Table 3. Overview of the measures used in the different studies.

Measures used in the thesis	Studies in which the measures are used	What is measured	Method
HbA1c	Studies I, III and IV	Measure of metabolic control	Swedish Mono-S method. Ref value <5.3%
Swe-DES-23	Study I	Four domains of empowerment and a total empowerment score	Five-point Likert scales
Interviews	Study II	Factors reported important for decision-making competence	Qualitative content analysis
Semantic Differential in Diabetes (SDD)	Study III	Attitudes towards diabetes and self-care	Semantic differential
Study-specific questionnaire	Study III	Perception of self-care, disease knowledge, independence, whether the teenagers felt disturbed by diabetes	Visual Analogue Scales ranging from 0-100
		Frequency of self-monitoring of blood-glucose	Three-point Likert scale
DCGM-37	Study IV	Self-reported physical, mental and social health, HRQL	Five-point Likert scales
DCGM-37, diabetes module	Study IV	Impact of the therapy on every day's life. Perceived disease severity	Five-point Likert scales
"Check your health"	Study IV	Self-reported physical, mental and social health, general quality of life and burden of diabetes	Vertical thermometer scales ranging from 0-100

HbA1c

HbA1c was measured using either high-performance liquid chromatography on filter paper or the DCA 2000, Bayer. The normal reference value is <5.3%. All values from the filter paper are transformed to Swedish Mono-S standard (Mono-S = DCCT standard x 1.0678–1.341 (Lachin *et al.* 2008), Danderyd Hospital laboratories), while DCA 2000 gives Mono-S values and is regularly calibrated toward a laboratory method.

The group differentiation, which was done to correlate burden of diabetes and health-related QoL with HbA1c in Paper IV, was based on 2007 ISPAD Guidelines, in which good metabolic control is defined as < 7.5%, suboptimal control 7.5-9% and high risk > 9 % (DCCT values) (Rewers *et al.* 2007). Swedish Mono-S values are approximately 1% lower than DCCT values.

Swe-DES-23

Empowerment was measured using the Swedish version (Leksell *et al.* 2007) of the American Diabetes Empowerment Scale (Anderson *et al.* 2000). The measure includes 23 questions, reflecting four domains of empowerment:

- Goal achievement
- Self-awareness
- Stress management
- Readiness to change.

The scores range from strongly agree (=5) to strongly disagree (=1). The four domains are summed into a total empowerment score. Table 4 shows an example of one question from the Swe-DES-23, in which a score of 5 means *I feel ready for changes*, and a score of 1 means *I am not at all ready to change*.

Table 4. An example of a question from the Swe-DES-23.

Concerning my diabetes I usually know what I am prepared to change:				
I strongly agree	I agree	Neutral	I don't agree	I strongly disagree
5	4	3	2	1

The Swe-DES-23 has been found to be a valid and a reliable measure of empowerment in adults with diabetes. There is no validated instrument for measuring empowerment in teenagers with diabetes.

Semantic Differential in Diabetes (SDD)

This questionnaire has been used in both clinical practice and research (Wikblad *et al.* 1990). The instrument measures attitudes towards diabetes as well as towards self-care, and has good reliability ($r = 0.93$) and validity when tested on adults with diabetes. It has also been found to be easy to understand and manage in clinical settings involving teenagers with diabetes. This instrument uses nine bipolar seven-point adjective scales, with 7 representing the most positive attitude and 1 the most negative.

After factor analysis, the scales were classified into four attitude factors (Wikblad *et al.* 1990):

- Factor 1 = self-esteem/autonomy: comprising the scales valuable–worthless, independent–dependent, unsafe–safe
- Factor 2 = object evaluation: including the scales dominant–submissive, difficult–easy
- Factor 3 = quality of life supporting factor: varied–monotonous
- Factor 4 = self-strength/vulnerability: including the scales free–constrained, tense–relaxed, and weak–strong

Study-specific questionnaire

The study-specific questionnaire was informed by the literature and clinical practice. Before starting the study, the questionnaire was pilot-tested in a group of teenagers with type 1 diabetes, and slight revisions were made.

A high score on the Visual Analogue Scale (VAS) means greater willingness to change treatment, better reported disease knowledge, more reported independence and fewer disturbances from diabetes. The scales were as follows:

- Willingness to change treatment:
Never (0) to Always (100).
- Knowledge of diabetes:
No knowledge at all (0) to I know everything (100).
- Independence in diabetes management:
Never (0) to Always (100).
- Disturbed by diabetes:
Always (0) Never (100).

Frequency of self-monitoring of blood glucose ranged from never/once in a while, to a couple times a week, to daily.

Interview guide

In the interviews, performed two weeks after the empowerment programme (II), open-ended questions were used. The interviewer used a pre-constructed interview guide for support during the interviews, which contained the following guidelines:

- How you experience living with diabetes
- How you found out you had diabetes
- Your experience during the very first period after the onset of diabetes
- A situation when you experienced stress
- A situation when you felt well
- How you handle your diabetes and self-care
- In what way you make yourself master your everyday life
- The role of friends and parents in managing of your diabetes self-care
- What attitudes towards diabetes you encounter in society

DCGM-37

The DCGM-37 measures HRQL in children with chronic conditions (Simoni *et al.* 2007), and was used in Paper IV to determine whether there was a correlation with the “Check your health” instrument. HRQL is defined here as a component of the more general QoL.

The DCGM-37 consists of 37 Likert-scaled items describing three domains: mental, social and physical. The items can be combined into a total score.

The DCGM-37 has shown good reliability in test-retest correlation measures (0.71-0.83). The authors also analysed the mean value difference in the test and retest scores using paired t-test, and no differences were found. Internal consistency was good, with Cronbach’s alpha values ranging from 0.70 to 0.87. The DCGM-37 showed only relatively low correlations (0.3-0.6) when compared with seven other questionnaires, except in the physical dimension, which had a correlation of 0.7 when compared with the PedsQL. Discriminant validity was found between gender, age and affluence. The recall period is four weeks, and there are both child and proxy versions.

DCGM-37, diabetes module

The questionnaire also has a diabetes-specific module, consisting of 11 questions (Baars *et al.* 2005). This module was tested in 207 people with diabetes (mean age 12.2 years; SD 2.8) in Europe (countries unknown). Ten items describe the “Impact” and “Treatment” domains and showed alpha values of

0.83 and 0.84, respectively. The eleventh question in the disease-specific module measures illness severity (11 a, b, c) and consists of three sub-questions with raw scores from 1 to 5: “How often have you had problems with your diabetes during the past year; How difficult has your diabetes been during the past year”; and “When did you last have serious hypoglycaemia?” The answers to these three sub-questions were used as description of perceived illness severity in Paper IV, and were arbitrarily distributed by the author into “low severity” (raw score 3-5) and “high severity” (raw score 1-2) categories.

Check your health

The “Check your health” instrument measures three subjective health parameters, namely physical health, emotional health and social functioning, while its fourth question measures overall QoL.

“Check your health” has shown to be valid and reliable when tested on adult diabetes patients (Wikblad *et al.* 2003). It has been found to be easy and practical to use in clinical settings involving teenagers with diabetes.

The instrument is constructed as vertical thermometer scales, whereby the person puts a mark on 100 if, for example, his/her physical health is very good, or on 0 if his/her physical health is very poor. On the same scale, the person reports what his/her imagined physical health would be without diabetes. This makes it possible to measure the difference between perceived physical health and imagined physical health without diabetes, for example. This difference is defined as “physical burden of diabetes”. When this difference resulted in a positive value, meaning that physical health was reported to be better with diabetes than without, for example, the burden was interpreted as the value 0. The marginal values used for no burden (0), low burden (<20), high burden (20-49) and very high burden (≥ 50) are arbitrary in this study.

Procedure

The empowerment programme and interviews

The procedure of randomization and measures in the empowerment study (I) are shown in Table 5.

Table 5. Flow chart for the intervention and outcome in the empowerment study.

Time	Intervention group (n=18)	Wait-listed control group (n=14)
0 months	HbA1c	HbA1c
	Randomization	Randomization
	DES - pretest	DES - pretest
	Intervention start	
6 months	DES, HbA1c	DES, HbA1c
		Intervention start
12 months	HbA1c	DES, HbA1c
18 months	HbA1c	HbA1c
24 months	HbA1c	HbA1c
30 months		HbA1c

HbA1c was collected from the medical records, and the researcher was blinded for the randomization when baseline values were collected. The teenagers completed the Swe-DES-23 before intervention and six month after programme attendance.

Data collected before and six months after intervention were used in between-group analysis, and data collected before as well as 6, 12, 18 and 24 months after programme attendance were used in within-group analysis.

The group facilitator was a diabetes nurse, who had attended a one-day course in problem-based learning before the programme started. The facilitator was also the researcher in the study. The group facilitator presented the theme for each session and led the discussion, but did not propose the topics to be discussed.

At the end of the empowerment programme, the participants were asked if they wanted to be interviewed (II). The interviews were completed at the diabetes clinic two weeks after completion of the programme, and were audio taped and transcribed verbatim by a secretary.

The schooner programme

In spring 2002, the attitude form and the study-specific questionnaire were sent to 90 campers and 90 non-campers (III) in the reference group, and were returned by mail to the researcher. Sixty-four (71%) campers and 61 (68%) non-campers answered the questionnaire and the attitude form.

HbA1c, disease duration and the use of CSII were collected from the medical records in both the intervention group and the reference group. Data on HbA1c were collected before as well as 6 and 12 months after intervention, and data on the use of CSII before and 12 months after the programme. The data collection in the reference group was done at the same time-intervals.

Validity- and reliability-test of “Check your health”

In the psychometric testing (IV), 204 teenagers completed the “Check your health” and DCGM-37 instruments, distributed by a diabetes nurse, before or after their regular visit at the diabetes outpatient clinic. Five of these were excluded, due to diabetes duration of less than six months. Forty-seven teenagers also answered the questionnaires two weeks later at home, and mailed them to the researcher.

Data on HbA1c, medical treatment and diabetes duration were collected from the medical records.

Data Analyses

Quantitative

Stat View 5.0 for Windows was used in the statistical analyses. The statistical analyses used are shown in Table 6.

Table 6. Statistical analyses used in the thesis.

	Analyses
Between-group analysis (I)	Unpaired Student's T-test
Within-group measures (I, III)	ANOVA repeated measures and Student's T-test
VAS and Likert scale (III)	Mann-Whitney test
Frequency of blood glucose and CSII (III)	Chi-square test
Floor and ceiling effects (IV)	% of results achieving highest or lowest score
Reliability and convergent validity (IV)	Pearson's product-moment correlation coefficient, Spearman's rank correlation
Group differences (IV)	ANOVA unpaired t-test, Mann-Whitney or KruskalWallis tests

Qualitative

Thirty-one interviews in Paper II were analysed using qualitative content analysis (Graneheim & Lundman 2004). The interviews were first read through by the first author several times to get a picture of the whole content. The next step was to organize the content concerning decision-making competence into meaning units. The following step was to shorten the text into condensed meaning units without losing its manifest meaning. These condensed meaning units were thereafter abstracted into codes, which were finally grouped into subcategories. Two researchers were involved in the process when codes were grouped into subcategories. These subcategories were internally homogeneous, but externally different. An example of the process is shown in Table 7.

Table 7. Example of meaning unit, condensed meaning unit code and subcategory.

Meaning unit	Condensed meaning unit	Code	Subcategory
You think they are inconvenient, nagging. But if they were to stop nagging, I would forget more often. They are extra careful, and I am their only child	They are inconvenient and nagging, but they make me remember	Nagging is inconvenient but helpful	Nagging is reminding

The last part of the analysis was to sort the subcategories into categories, which can be seen as an expression of the manifest content in the interviews. The procedure from codes to categories is shown in Table 8.

Table 8. Examples of codes, subcategories and categories from the content analysis of the interviews concerning decision-making competence.

Codes	Subcategories	Categories
I know the connection between food, physical activities and the effects on my blood glucose.	Making abstractions	
Time has taught me how I want to manage my diabetes, and there is no one else who knows better than I do.	Trusting own capability	Cognitive maturity
I want to make more decisions than I do today. The doctor knows more and it is nice when he/she can make some decisions.	Self-knowledge	
My mother and father wanted me to tell others, although I thought it was unpleasant.	Constructive	
I seldom eat with my family, who have no routines at all.	Passive destructive	Parent involvement
Daddy only gives sweets to my little sister and not me, and I get angry.	Active destructive	

Finally, the latent content of the categories was interpreted and provided the overall theme, with meanings from all the categories and subcategories. The procedure from codes to interpreting the theme was constantly discussed and compared back and forth by the two authors (II).

Ethical considerations

All four studies were approved by the local Ethics Committee (I and II, 00-155 III, 02-070, IV, 2005/1352-31). The teenagers and one or both parents gave written consent to take part in all studies, and were informed that they could withdraw from the intervention whenever desired. Information about the results of the studies will be presented to the teenagers and their families in the form of the Swedish summary of the thesis.

The wait-listed design in Paper I was chosen in order to be able to offer the same education programme to both the intervention group and the control group. This design is often used in educational randomized studies, because if a programme has positive effects it would be unethical to exclude anyone from it.

One risk involved with patient education is that the group leader uses a paternalistic approach, which may make patients passive. Empowerment is grounded in a patient-centred approach, in which the education is based on the group members' reality, dialogue and reflection, and this may protect them from the paternalistic disadvantages. On the other hand, the empowerment approach may lead to some issues being dropped, even if the facilitator feels they are significant. It is important that the problem posing and the reflections are well grounded by the group members, to make the group facilitator feel safe and trust the decisions they make.

The decision to let the group decide whether or not to invite parents may have been perceived by the parents as unfair, but the empowerment approach does not allow the facilitator to decide against the group members' will.

The interviews with the group members after the intervention (II) may have raised different feelings. It would have been beneficial if the teenagers had got the opportunity to reflect on the interview after some weeks, but this was not practical as the interviewer lived in another city.

The schooner programme was offered to nearly all teenagers at the clinic. It was held during school-days, which may have prohibited some teenagers from attending. On the other hand, holding the camp on a holiday or weekend might have decreased the potential for the programme to continue.

Results

Empowerment group education programme

Metabolic control

There were no significant differences between the intervention group and the control group, or in the intention to treat analysis, six months after programme attendance, which is shown in Table 9.

Table 9. HbA1c values before and after intervention.

	Intervention group, per protocol (n=18)	Control group, per protocol (n=14)	Intervention group, ITT (n=28)	Control group, ITT (n=27)
Before intervention	7.4% (SD=1.2)	8.1% (SD=1.8)	7.8% (SD=1.3)	8.2% (SD=1.6)
Six months after intervention	8.2% (SD=1.7)	8.4% (SD=1.3)	8.4% (SD=1.6)	8.3% (SD=1.4)
Difference	0.8	0.3	0.6	0.1

In within-group measures, teenagers >14 years of age (n= 15) had increased their HbA1c six months and one year after attendance (p<0.01), while in the younger teenagers (≤14 years, n=17), HbA1c was unchanged (Figure 2).

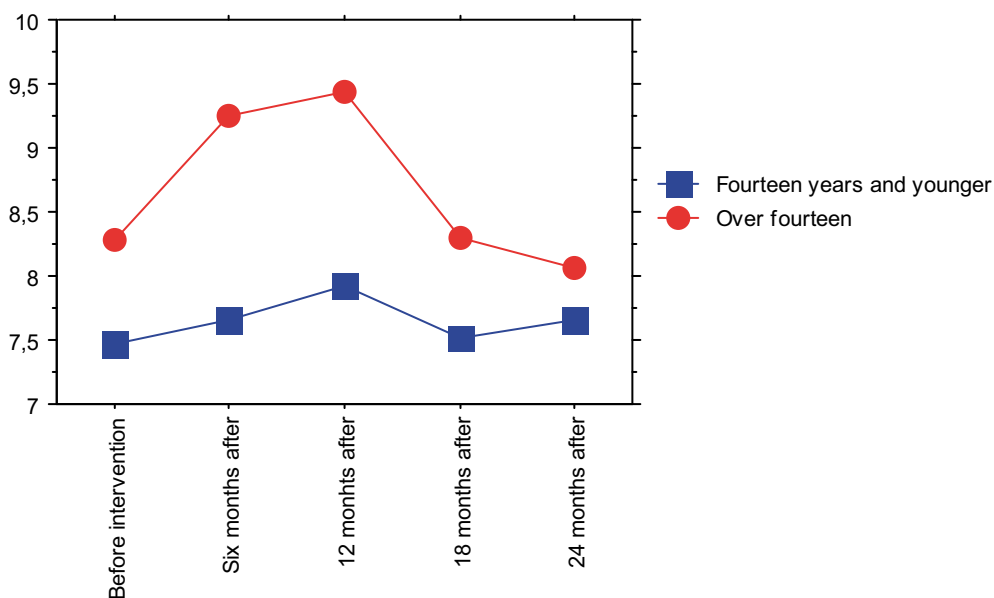


Figure 2. Mean values and 95% confidence interval (CI) for HbA1c in relation to age in within-group comparison, before and 6, 12, 18 and 24 months after the intervention.

Missing values in teenagers ≤ 14 years: Before and six months after intervention: 1; 24 months after intervention: 3

Empowerment

All empowerment factors as well as the total score for empowerment were unchanged six months after intervention, when the intervention group was compared to the control group. In within-group measures, the factor “readiness to change” had significantly increased from 3.9 (SD=0.5) to 4.1 (SD=0.5) ($p < 0.05$, 95% CI of the difference – 0.38, - 0.05) six months after programme attendance, but no age-differences were found.

Parent involvement

The six groups handled the offer to invite their parents to a group meeting differently. Two groups invited the parents (a), two did not (b), and two let the facilitator meet with the parents (c). There was no significant difference in baseline HbA1c between-groups a, b and c (7.6, 7.5, 7.8%, respectively). In group a, HbA1c decreased from 8.8% (SD=1.1) one year after intervention to 7.6%, two years after intervention (SD=1.3; $p<0.05$, 95% CI of the difference 0.37-2.26). In group b, HbA1c increased significantly one year after intervention from 7.6% (SD=0.9) to 8.6% (SD=0.8; $p<0.05$, 95% CI of the difference -1.62 - -0.16), and in group c no significant changes were found. In between-group comparisons (groups a, b and c), no difference was found.

Factors affecting decision-making competence in diabetes management

The analysis of the interviews resulted in five categories of issues the teenagers reported as being important for decision-making. The interpretation of the latent content gave the overall theme:

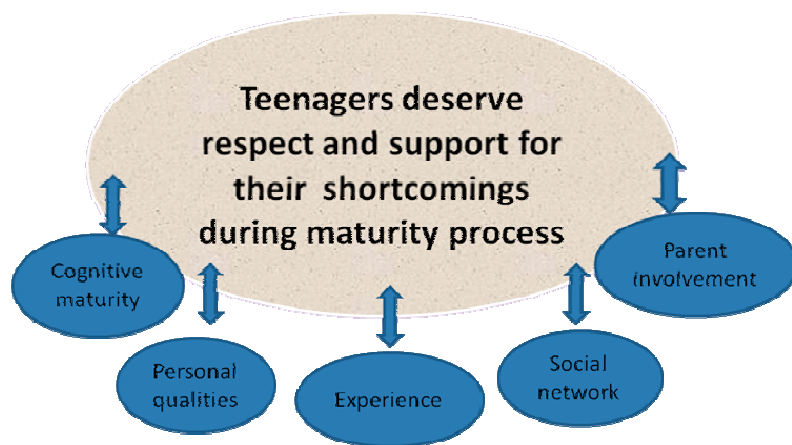


Figure 3. Overall theme and categories that interact in the maturity process towards independent decision-making competence.

The latent theme was built on the manifest content of the categories, sub-categories and codes. The three categories (cognitive maturity, personal qualities and experience) may not be mature enough during adolescence and

are therefore interpreted as possible shortcomings. Social network and parent involvement are seen as resources that may balance these shortcomings during the transition period if they are constructive instead of destructive.

Cognitive maturity

The teenagers described cognitive maturity in terms of being able to make abstractions, trusting one's own capability and self-knowledge. Abstract thinking means being able to see connections between things like insulin dose, food intake and blood glucose values, being able to prioritize the best choices and seeing both the long-term and short-term consequences of these choices. Seeking knowledge and taking one's own initiatives, making one's own plans and setting goals, as well as having the capacity for problem solving, is seen as trusting one's own capacity.

To have insight and consciousness is related to self-knowledge.

"I dance. Twice a week. I do feel much better if I have some physical activities. You don't feel tired and faint. After exercise, I become more sensitive to insulin. Then I have to decrease my insulin dose." (Interview, girl, 14 years of age)

Personal qualities

The personal qualities that enable decision-making are described as flexibility and intuition, self-reliance and self-strength. Flexibility and intuition may involve daring to try an insulin dose even if you feel unsure that it is the best choice. This fits well with self-reliance, which is described as "I trust my own knowledge, I know how I feel and what I need. I have the courage to stand up for my decisions". A strong wish to make one's own decisions and to have control is described as self-strength.

"My blood glucose is very high, because a while ago I stopped taking my injections...not all, but most of them. I felt very sick. My blood glucose is still high but it's starting to decrease. I just got tired of them. I didn't feel well, I felt sick all the time, and it was like when I first got diabetes. Now I have the insight that I feel much better when I take the injections, and now I really try, because I know how I feel if I don't take them. It feels much better to take the injections." (Interview, girl, 15 years of age)

Experience

Experience in diabetes management may be gained through reflection and by making mistakes. Trying different solutions and experimenting also leads to new experiences.

“I very often draw conclusions from earlier occasions. Then I have to think... think what amount of carbohydrates the food contains, think about what I did last time...” (Interview, boy, 12 years of age)

When the teenagers described experience they gained from others, it was primarily from members in the empowerment programme. A person in the same situation may have the same problems, which may lead to new solutions to these problems.

Social network

The social network comprised friends, group members from the empowerment programme, members of the diabetes team and other people around the teenager. This network should share in decision-making and responsibilities, but should also let the teenager decide. These people should be there to offer support and help, and the teenager wants to be trusted and listened to. The teenagers want these people to be informed about diabetes, so that a safe environment is created.

“It is the doctors and me. They know, they know when to increase or decrease, they know everything that is going to happen. I often know which dose I should take.”

. (Interview, boy, 15 years of age)

Parent involvement

As parents were described as so much more important than other people in the social network, this became a category of its own. It was clear from the interviews that parents can be both constructive and destructive in their involvement in decisions about diabetes management.

As in the descriptions of the social network, teamwork and safety were two subcategories that had constructive influence on decision-making. Sharing knowledge and responsibility and getting help when one's knowledge is lacking is described as team work. This subcategory also contains coaching and reminding parents, and getting help solving problems. Constructive parent involvement is also described in terms of creating safety.

“My father, he can discuss things and ask what I think. He knows a lot about diabetes, and because of that it is fun to discuss things with him. It feels like he knows what I can handle and in which situation I still need help. When he reminds me, I don't get irritated like I do when my mother does, because she hassles me.” (Story created by the author during interview analysis.)

The schooner programme

Metabolic control and treatment

HbA1c was unchanged in both participants (7.5% [SD=1.3] vs. 7.7% [SD=1.3]) - and non-participants (7.6% [SD=1.6] vs. 7.6% [SD=1.5]) one year after diabetes camp attendance.

Before the camps the number of attendees and non-attendees, using CSII was virtually the same (11/64 vs. 9/61), but after the camps the attendees used it to a higher degree than non-attendees did (22/64 vs. 12/61) ($\chi^2=3.8$, $df=1$, $p=0.05$).

Attitudes towards diabetes and self-care

The teenagers participating in the camps had more positive overall attitudes towards diabetes ($p<0.0001$; $Z= -5.6$), higher self-esteem ($p<0.0001$) and less vulnerability ($p\leq 0.001$), and viewed their diabetes more positively ($p<0.001$). Overall attitudes towards self-care were also more positive in the camp group ($p<0.001$; $Z= -3.8$) than in the reference group. The campers had higher self-esteem/autonomy ($p<0.0001$) and felt less vulnerable ($p<0.05$).

Self-management

The campers measured blood glucose more often ($p<0.01$; $df=2$; $\alpha^2=9.5$), and felt less disturbed by their diabetes than did non-campers ($p<0.05$; $Z= -1.97$).

There was no difference between the two groups concerning reported diabetes knowledge, reported independence or frequency of changing treatment.

Attendance rate

Two hundred and seventy-seven people between 12 and 17 years old were invited to participate in the empowerment programme. Of these 277, 55 attended an information meeting and were randomized. Thirty-eight people started the programme (13.7%) and 32 (11.5%) attended at least four out of the six group meetings.

Two hundred-ninety people between 14 and 17 years old were invited to attend the diabetes camps. After 3-5 invitations were sent each person, from 1998 to 2001, 90 (31%) people attended the camp programme.

The psychometric properties of the “Check your health” instrument

Reliability

The reliability of the instrument was satisfactory on group level. Self-reported health showed a correlation coefficient between 0.78 and 0.65, and self-reported imagined health without diabetes was 0.73-0.59.

Scoring

We found no floor effect on any of the four health dimensions or as reported in imagined health without diabetes, while the ceiling effect was high for both the health dimensions (ranging from 5 to 30%) and imagined health without diabetes (8-30%).

Convergent validity

The correlations between “Check your health” and the DCGM-37 were all significant, with correlation coefficients between 0.38 and 0.62. The correlation between “Impact” in the disease module of DCGM-37 showed low correlations with burden of diabetes in “Check your health” (0.28-0.38).

Discriminant validity

“Check your health” discriminated between reported disease severity and physical/emotional health as well as between the physical/emotional burden of diabetes. It also showed a gender difference in reported physical health, QoL and burden of QoL.

Metabolic control (HbA1c) was correlated to all dimensions of burden of diabetes except social burden, but regarding reported health only physical health was correlated to HbA1c.

When reported health was compared with burden of diabetes, a higher burden was correlated to poorer health. The pattern was the same when comparing the DCGM-37 with burden of diabetes. The missing values were few, ranging from 3 to 6 (1-3%), and were not included in the reported mean values.

Discussion

General discussion

The findings in the thesis showed that no improvement in HbA1c or empowerment factors had been achieved after the empowerment programme in the between-group comparison. In within-group comparison, teenagers over 14 years of age had significantly increased their HbA1c six and 12 months after attending the empowerment programme, but HbA1c had been restored 18 and 24 months after intervention. This result is in accordance with another study, in which HbA1c increased when the intervention was completed and was restored 12 months later (Anderson *et al.* 1999). It would have been interesting to follow HbA1c for a longer time, but it would have been difficult to interpret the results, as the natural course of metabolic control is that it improves in late adolescence.

The baseline values in the intervention group and the control group differed between 7.4 and 8.1%. The difference was smaller in the ITT-groups (7.8 and 8.2%), which indicates that people with poor metabolic control dropped out of the intervention group.

There was a tendency that readiness to change increased after the empowerment programme. In the qualitative evaluation of the programme, the teenagers expressed that the programme had great significance for sharing experiences and identifying with others in the same situation (Karlsson *et al.* 2007). One interpretation of the results from Paper I, and from the study by Karlsson *et al.*, indicates that the empowerment programme started an empowerment process.

One may wonder why the deterioration in HbA1c was found only in the older teenagers. Parents of younger children (8-12 years) have been shown to be more involved in diabetes management than were those of older children (13-17 years) (Anderson *et al.* 2002). Both parents and teenagers in the empowerment programme were informed that the empowerment education aimed at supporting the teenagers' independent decision-making. It is possible that the parents of the older teenagers (>14 years) withdrew their involvement in the diabetes management, and that these teenagers were not mature enough to handle this process without the side effect of impaired metabolic control. That would also explain why HbA1c did not change in the younger teenagers.

Paterson and Thorne (2000) described the way towards becoming an expert in diabetes management as a movement through four phases: passive compliance, naïve experimentation, rebellion and active control. Naïve experimentation and rebellion are seen as essential phases in reaching control. The development was both trajectory, with sequential phases, and age-related. There is a possibility that the empowerment programme precipitated this process, and that the deterioration in metabolic control and increased readiness to change constituted a way towards reaching control over the management of diabetes.

Overall, educational studies evaluated in two reviews showed low significant effects on metabolic control or psychosocial factors, despite different approaches (Hampson *et al.* 2001b, Murphy *et al.* 2006)

Three different programmes have been published recently, in which metabolic control had significantly improved 18-24 months after intervention. Two of the programmes used a behavioural approach, one included adults and one teenagers (Amsberg *et al.* 2008, Wysocki *et al.* 2007, Wysocki *et al.* 2008). The third study evaluated motivational interviewing in teenagers, and the content of that programme was similar to that of the empowerment programme in this thesis (Channon *et al.* 2007). All three interventions were diabetes-specific, one pinpointed parent involvement, and all were maintained for at least six months. The teenager study using a behavioural approach was based on group education, while the motivational interviews were conducted on individual bases.

In their review, Hampson *et al.* (2001) reported that there was no study showing any advantage in individual compared to group interventions. The empowerment intervention in this thesis was maintained for six weeks, compared to at least six months in the three studies above that showed positive effects. This may support the possibility that a programme's length is important.

In the interview two weeks after the intervention, the teenagers from the empowerment programme evaluated it (Karlsson *et al.* 2007). The findings showed that teenagers evaluated group meetings with like-minded individuals as significant, and they also described how the meetings contributed to their sense of community. Other findings were that the programme encouraged discussions identified by the teenagers as close to their circumstances. They also discovered a great deal of diabetes-related problems that they had in common, which helped them to identify with other youths and bound them together. These results indicate the importance the programme had for the teenagers, and should be taken into consideration when interpreting its quantitative effects.

Decision-making plays an important role in the definition of empowerment. The literature on teenagers' decision-making competence reports that teenagers lack several competencies that contribute to decision-making, for example advice-seeking, goal setting, identifying a problem, and prioritizing

different choices (Byrnes 2002, Mann *et al.* 1989, Ormond *et al.* 1991). The teenagers have described factors they perceive as important for their decision-making competence. The description of decision-making given by the teenagers resulted in five categories: cognitive maturity, personal qualities, experience, social network and parent involvement. These factors fit well with the results found in another study (Steinberg 2005), that adolescents' decisions are not only cognitive but are also affected by feelings and social influence. The literature indicates that there is a correlation between teenagers' decision-making competence and the need for parent support (Graue *et al.* 2005b, Hanna *et al.* 2003), and even that this support may be more important than the young people's own capability (Mårtenson & Fägerskiöld 2007).

There were indications in the empowerment programme that parent involvement may have an influence on metabolic control, which is supported by others, saying that teenagers risk management problems if parents push their teenagers too hard towards autonomy and that metabolic control is best when parent responsibility is maintained in teenagers with low self-efficacy (Graue *et al.* 2005b, Palmer *et al.* 2008, Wysocki & Greco 2006). Parent-adolescent communication has been described and synthesized in a review, including articles between 1985 and 2006 (Dashiff *et al.* 2008). The results showed that support, conflict, control, involvement and emotional expression were important concepts linked to diabetes outcomes in adolescents.

Satin and co-workers (1989) showed positive effect on metabolic control after a multifamily group intervention for teenagers with diabetes. Both the group with multifamily group intervention (MF) and the group with MF + parent simulation of diabetes showed a significant decrease in HbA1c. The problem with Satin's study is the small sample of 32 people, who were randomized stepwise into three different groups. Satin also discussed whether the families attending the study were extra interested in behavioural and psychological interventions, as well as more concerned about their children's metabolic control than other parents were. There were no reports of dropouts in the study and no intention-to-treat analysis. These biases imply that the results have to be interpreted with caution, but the model of the programme is nonetheless interesting and may be able to be used, with an empowerment approach, in a new randomized study.

The teenagers in the empowerment programme reported different factors of importance for decision-making, and their rich description of both constructive and destructive parent involvement may have significance for future interventions including parents. The qualitative and quantitative results from the empowerment study, the evidence that teenagers are not fully mature decision-makers and findings that parent involvement should be withdrawn according to the teenagers' maturation together support that empowerment education may be suitable for teenagers if parent training is included in the programme. This training should promote parent-adolescent teamwork

and decreased controlling communication, which may diminish diabetes conflicts and increase parent-adolescent satisfaction as well as adolescents QoL through the transition into adulthood (Dashiff *et al.* 2008).

The schooner programme had no effect on metabolic control, and there is limited evidence on the effects after camp attendance in the literature (Hampson *et al.* 2001a, Norris *et al.* 2002). The notion that the use of CSII increased after camp attendance may be in concordance with the result from the empowerment intervention, which was an increased readiness to change in within-group measures. Together, these results may support the idea that meeting with others could be an inspiration for a willingness to change.

One question that should be raised is whether people choosing to attend educational programmes in some way differ from those who do not. Teenagers who attended the schooner programme showed significantly more positive attitudes towards both their diabetes and their self-care than did those who did not want to participate. Data on attitudes or other factors affecting attendance have not been found in the literature on educational programmes for teenagers with diabetes.

Educational programmes that have positive effects on the participants should attract as many people as possible. It is difficult to get information from many studies on patient education concerning the eligible population before the inclusion- and exclusion proceedings. In recent RCT studies a flow chart has to be presented (Adolfsson *et al.* 2007). In the two interventions in this thesis, the attendance rate varied between 11 and 31%, whereby in the latter study each participant was invited to participate in the schooner programme up to five times. This is in accordance with other studies, in which Schlundt *et al.* (1999), for example assessed a summer school for teenagers, and only 7% of the eligible population attended the programme. In two other studies, one presented complete data on 28% of the eligible population, and the other 16 % (Channon *et al.* 2007, Wysocki *et al.* 2008).

It has to be taken into consideration that at least 70% of the patients in these studies either declined or were excluded from attendance in the educational programmes, and that these people may have had more negative attitudes towards their diabetes and self-care, which can be an obstacle to attendance in group education programmes.

We thus have to consider the need to offer all patients education. It seems that education is most effective when it is integrated into routine care (Murphy *et al.* 2006), and this might make a larger amount of patients eligible for educational programmes.

Group education may not suit all teenagers with diabetes, and it seems that at least 70% of patients prefer not to participate in group education. As it is important for all teenagers to receive education about diabetes and there is no evidence that group education has more positive results than individual education does, the diabetes teams also has to offer a well structured individual education plan for each patient.

Empowerment and a patient-centred approach may be a way to strengthen teenagers in individual meetings as well. Jolly and co-workers (2007) presented a guide for nursing practice on how to understand teenagers' voices by allowing them to share their health stories in a non-judgemental dialogue, grounded in Freire's philosophy. It is possible to use this model to let teenagers with diabetes give a voice to their health story. Including the teenagers' ideas and perspectives when planning and implementing educational programmes may make health services more attractive to young people (Rosenfeld *et al.* 2000).

To succeed with education for teenagers, it may be important that the team exercise a mutual approach towards the influence of adolescence on individuals' behaviour, as well as a joint approach towards education.

Seeing adolescence as a transition towards adulthood makes this period in life both a developmental-maturational transition and a role shift (Murphy 1990). The framework of transition makes it possible to set goals within a longer perspective, which means that several factors may have implications for a successful transition in teenagers with diabetes. In their literature review, Schumacher and Meleis (1994) found that meanings, expectations, level of knowledge and skills, the environment, level of planning, and emotional and physical wellbeing were factors that had an influence on the transition process. From the carer's perspective, this means understanding the meaning of the transition from the perspective of those who experience it, preparing people so that they have reasonable expectations concerning the transition, planning for this period by finding key people and supporting the communication among these people. It may also be offering education, and promoting mental and physical wellbeing during transition. Figure 4 describes how different factors studied in this thesis may influence the transition in either a positive or negative direction.

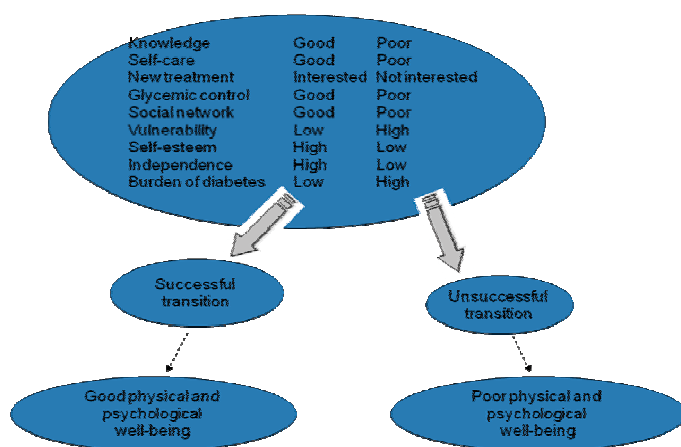


Figure 4. Factors from the thesis facilitating or aggravating the transition.

Choosing the transition approach, means that we may have to assess factors other than simply metabolic control when evaluating educational programmes for teenagers with diabetes. The effect size on psychosocial parameters is shown to be larger than effects on metabolic control (Hampson *et al.* 2001b, Murphy *et al.* 2006), but there is no evidence today that improvements in psychosocial factors have a long-term effect on metabolic control.

One problem is that psychosocial factors are measured using many different instruments. Another problem is that these factors are often not measured at all (Murphy *et al.* 2006). The ISPAD Guidelines from 2007 recommend that different domains of QoL should be assessed on a routine basis. According to Br lde and Tengland, neither QoL (Br lde 2003) nor health (Br lde & Tengland 2003) are possible to measure properly even on an ordinal scale, but the authors still say that we have to measure for practical reasons. There is a great problem in defining these concepts, even if there are studies that try to clarify the distinction between perceived health and QoL (Smith *et al.* 1999, Zullig *et al.* 2005). Another concept often used in the literature is HRQL, but the definition of this concept is difficult to distinguish from QOL. Wallander *et al.* (2001) suggest that only two concepts should be used: perceived health and QoL.

If we are to evaluate health and QoL on a routine basis, we need an instrument that is easy for young people to understand, does not take too long time to complete, is easy for health care personnel to evaluate and is reliable and valid.

“Check your health” is an instrument that measures perceived health and QoL as well as perceived burden of diabetes. The instrument has only four

thermometer scales that are easy for young people to understand. The scales measure from 0 to 100, and need no transformation.

The reliability of “Check your health” was satisfying on a group level, with correlation coefficients between 0.6 and 0.8, while its use on an individual level needs correlations above 0.7 (Polit & Beck 2008).

The convergent validity of “Check your health” showed that all correlations with the DCGM-37 were significant (Pearson $r=0.26-0.66$). When the DCGM-37 was compared to the KINDL-R instrument comparable correlations were found (Pearson $r=0.12-0.64$), which was interpreted as moderate.

“Check your health” did show discriminant validity when perceived health was compared with metabolic control, gender and disease severity. HbA1c was correlated to physical health, gender to QoL and disease severity to both physical and mental health.

Burden of diabetes showed stronger discriminant validity. HbA1c was correlated to both physical and mental burden, as well as burden on QoL. Gender was correlated to both physical burden and burden on QoL, while disease severity correlated to physical and mental burden of diabetes.

When burden of diabetes was compared with perceived health, high burden was significantly correlated to low perceived health and QoL, which means that the measure of burden of diabetes is sensitive.

The validation of the “Check your health” instrument was not completed by proxy, which is recommended for enhancing validity (Eiser & Morse 2001); this is recommended for further studies. The same instrument can be used on parents with only small changes to the text.

The high ceiling effect, especially on the social relations domain probably reflects the possibility that diabetes has a small impact on social relations in teenagers with diabetes (Varni *et al.* 2007), but it limits the instrument’s potential to evaluate improvements in this domain. On the other hand there was no floor effect, which ensures evaluation of deteriorations of perceived health and burden of diabetes.

The overall conclusion is that “Check your health” is a useful measure in teenagers with diabetes on a group level.

Methodological considerations

HbA1c increased in within-group measures after the empowerment programme, and it is possible that the sample size did not give enough power to show this effect in between-group comparison. The power calculation was counted with a SD of 1.0 and an expected HbA1c change of 1%, which resulted in a group size of 16 people in each group. The results in the Paper I showed that SD was close to 1.5, and Murphy and co-workers (2006) calculated using $SD=1.7$. For a lower change in HbA1c and a higher SD to have been interpreted as clinically significant, the groups would have had to be

larger to receive enough power. A solution to this would have been to invite teenagers from more than one children's hospital.

The Swe-DES-23 was not validated for teenagers. The age of the participants was between 12 and 17 years, which mean that none had difficulties reading the questions. Some younger patients did have small problems understanding the questions, which may have biased the results. It might be preferable to validate an empowerment measure for young people with diabetes to receive valid data after empowerment implementations.

The interpretation of the results from Paper III, the diabetes camps, is a bit problematic. We wanted to elucidate discriminating factors between teenagers attending camp and those who did not. The questionnaire and SDD were sent to 90 campers and 90 non-campers once, in spring 2002. This was after camp attendance, which means that the significant differences found may have already been there before the camp interventions. As the SDD and questionnaire were sent to all campers and non-campers at the same time, this means that the time since camp attendance was different for those from different camps when they completed the two measures. On the other hand, the difference in attitudes between campers and non-campers was interpreted as too large to be an effect of the camp.

One may also take into consideration that it is difficult to know whether effects of camp interventions are due to the education *per se* or to the whole concept of diabetes camp (Hampson *et al.* 2001b).

Despite the methodological weaknesses in Paper III, the results are rather convincing that teenagers who are willing to attend camp have more positive attitudes towards diabetes and self-care than teenagers who are not.

Another question that has to be raised is the group facilitator's impact on the results of a patient education programme. It may be difficult to change paradigm from the role of a teacher to that of a group facilitator (Rosenqvist 2001, Thors-Adolfsson *et al.* 2004) but using the researcher as group facilitator may ensure that the same approach is used throughout the study. In Paper I the researcher was also the facilitator, which should ensure that the same approach was practiced in all groups. There is a possibility that the researcher's deep interest and enthusiasm in the implementation of the programme may have influenced the results in a positive direction.

The validity would have been increased in the interview study (Paper II) if feedback on the findings had been given by the teenagers who were interviewed. This was not done, due to practical difficulties, but the possibility of telephone feedback might have solved the problem. The fact that the interviewer was not initiated in diabetes management could have either strengthened or weakened the results.

In the testing of the "Check your health" instrument, the questionnaire was distributed by a diabetes nurse before or after the clinical visit. In studies on adults, the patients usually return the questionnaires by mail, but to be sure the teenagers answered the questions without help from their parents,

they completed the two instruments at the outpatient clinic, before or after a regular visit. The mode of administration may influence the results of the measure (Hanmer *et al.* 2007). It may be that some of the teenagers were anxious to leave the hospital, and that the home setting would have been calmer for them, but the importance of valid answers was prioritized. Another disadvantage of a mailing procedure is the problem with dropouts, which is solved with a consecutive sample.

Conclusions

Empowerment education for teenagers with diabetes made young people more interested in changes, but did not improve metabolic control. Such programmes have to take young people's decision-making maturity into consideration and involve parents of teenagers in low and middle adolescence in the programme. The purpose of parent involvement should be to increase family teamwork and the teenager's perception of safety.

Educational programmes that are not integrated into routine care engaged 11 to 31% of the teenagers, and these teenagers had more positive attitudes towards diabetes and self-care than non-participants did. In order to engage as many teenagers as possible in educational interventions, group education may be integrated into routine care, but structured individual education should also be offered to teenagers who do not like being in a group.

Camp attendance had no influence on metabolic control, but increased the interest in a new treatment. This supports the results from the first study, which increased teenagers' readiness to change. Meeting with others in the same situation probably inspires teenagers towards openness to change.

The "Check your health" instrument is a useful measure for evaluating perceived health and perceived burden of diabetes in teenagers between 12 and 17 years of age. The results of the validity and reliability test limit the use of the instrument to measures on a group level only. "Check your health" can be used in clinical routine evaluation or in the assessment of different interventions. A proxy version should be tested, to further enhance the instrument's validity.

Svensk sammanfattning

Utbildning av ungdomar med diabetes är en nödvändig del av diabetesvården. Under puberteten ändras hormonbildningen, insulindosen kan behöva ökas kraftigt pga. att kroppen blir okänslig för insulin.

Under tonårstiden skall ungdomar successivt frigöra sig från föräldrarna, och ta mer och mer eget ansvar för sin diabetes.

Typ 1 Diabetes är en sjukdom som inom några år efter debuten leder till total avsaknad av insulin, och också avsaknad av det styrsystem som reglerar insulintillförseln. Det innebär att personer med typ 1 diabetes själva måste lära sig att reglera insulintillförsel med hänsyn till olika faktorer som bl a mat, fysisk aktivitet, olika hormoners påverkan på insulinbehovet och kroppens känslighet för insulin. Insulin reglerar metabolismen av både fett, protein och kolhydrater, och en felaktig dosering kan leda till antingen att blodsockret blir för högt eller för lågt. Insulinbrist, vilket leder till högt blodsocker, kan orsaka både akuta och långsiktiga komplikationer, och lågt blodsocker kan framkalla obehagliga symptom eller medvetenlöshet och kramper.

Olika modeller av patientutbildning för tonåringar med diabetes har prövats, men inga studier har kunnat förordna något speciellt program. Effekten av patientutbildning har hitintills visat sig vara låg till måttlig, med något större effekt på psykosociala faktorer jämfört med metabol kontroll (HbA1c). Den första studien i avhandlingen (I) var en randomiserad studie, som utvärderade en empowermentutbildning i grupp för tonåringar, 12-17 år, med diabetes. 55 av tillgängliga 277 ungdomar lottades till interventionsgrupp eller kontrollgrupp, 38 påbörjade programmet och 32 deltog i minst 4/6 möten. Empowerment är ett patientcentrerat förhållningssätt, vilket innebär att diskussioner och reflektioner bygger på gruppdeltagarnas egna erfarenheter. Målet är att gruppmedlemmarna skall bli medvetna om vad de behöver förändra, lägga upp en handlingsplan, och ta kontroll över sin sjukdom. Utbildningen gav vid jämförelse mellan interventionsgrupp (n=18) och kontrollgrupp (n=14) inte någon effekt på den metabola kontrollen (HbA1c) eller på någon av de studerade empowermentfaktorerna. Vid en sammanslagning av grupperna ökade faktorn ”förändringsbenägenhet”, och den metabola kontrollen försämrades för tonåringar över 14 år. Eftersom några grupper valde att involvera sina föräldrar i programmet, och vissa valde att inte göra det, kunde vi också visa att föräldramedverkan hade viss positiv effekt på förändringen av den metabola kontrollen.

För att kunna hantera sin diabetes självständigt, måste man vara mogen att flera gånger dagligen kunna fatta beslut som gäller behandlingen. Det finns stöd för att ungdomar inte har samma förmåga som vuxna att kunna fatta rationella beslut.

Ungdomarna intervjuades två veckor efter avslutad utbildning (II), och intervjuerna analyserades avseende ungdomarnas syn på faktorer som påverkar förmågan att fatta beslut. Fem faktorer av betydelse framkom; kognitiv förmåga, personliga kvaliteter, erfarenheter, socialt nätverk och föräldramedverkan. Ett övergripande tema, en tolkning av innehållet av intervjuerna, beskriver ungdomars syn på förmågan att fatta beslut:

”Vi förtjänar respekt och stöd på grund av våra brister under mognadsprocessen”.

Ungdomarna gav en rik beskrivning av föräldramedverkan, som kan vara både konstruktiv, passivt destruktiv och aktivt destruktiv.

I en tredje tvärsnittsstudie (III) utvärderades grupputbildning i samband med lägervistelse på en segelskuta. Nittio ungdomar mellan 14-17 år deltog i sex olika läger. Utvärderingen visade att programmet inte hade någon effekt på metabol kontroll, men intresset för att byta från vanliga injektioner till insulinpumpbehandling ökade. De ungdomar som valt att delta i lägret hade betydligt positivare attityder till sin sjukdom och till egenvård än de ungdomar som valde att avstå från utbildningen.

Deltagarfrekvensen i de båda utbildningsprogrammen (I, III) var 11% respektive 31%. Skillnaden förklaras av att ungdomarna i studie III, fick upprepade möjligheter att delta, medan de i studie I erbjöds en gång.

I den sista studien utvärderades ett formulär, som mäter upplevd hälsa och livskvalitet, samt upplevd diabetesbörda. Instrumentet är utformat som en vertikal termometer, där man från ena hållet graderar sin upplevda hälsa från 0-100, och från andra hållet sin hälsa om man inte hade haft diabetes (0-100). Metoden möjliggör att man mäter avståndet mellan de två punkterna, och därmed får ett mått på upplevd diabetesbörda. En relativt stor del av ungdomar skattade sin hälsa, framför allt sociala relationer, till 100 på skalan, vilket innebär att det är svårt att mäta förbättringar. Detta resultat stämmer överrens med tidigare studier, som visat att ungdomar med diabetes skattar högst hälsa jämfört med ungdomar med andra kroniska sjukdomar. Den del av instrumentet som mäter upplevd diabetesbörda visade sig vara mest sensitiv. Instrumentet visade sig vara tillräckligt stabilt och trovärdigt för att kunna användas på ungdomar med diabetes på gruppnivå.

Sammanfattningsvis visar avhandlingen att empowermentutbildningen troligen satte igång en empowermentprocess, vilken de äldre ungdomarna inte klarade av att hantera. Det kan bero på att ungdomarna under 15 år fortfarande fick stöd från sina föräldrar, medan de äldre ungdomarna förmodades klara förändringen på egen hand. Slutsatsen blir att framtida empowermen-

tutbildningar för tonåringar bör inkludera föräldrar, som får diskutera på vilket sätt de kan vara ett stöd för tonåringarnas förändringsarbete. Eftersom det inte finns visat att grupputbildning har bättre effekter än individuell utbildning, måste man strukturera båda formerna av patientutbildning för att nå ut till så många ungdomar som möjligt. Utbildningen bör också integreras i den kliniska verksamheten, och ha lång uppföljningstid, för att nå bästa möjliga effekt.

Instrumentet ”Ta tempen på din hälsa” är ett stabilt och trovärdigt instrument som kan användas i olika sammanhang, bland annat för att utvärdera patientutbildning.

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