SIRKKU TULOKAS

Diabetes in Adolescence – a New Approach to Patient Education

The Problem-based Learning Method

University of Tampere
Tampere 2001

Diabetes in Adolescence – a New Approach to Patient Education

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ACADEMIC DISSERTATION

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CONTENT

ABBREVIATIONS ix

INTRODUCTION xi

REVIEW OF THE LITERATURE 13

1 Prevalence of diabetes in adolescence 13

2 Goals of treatment of diabetic adolescents 13

3 Transfer from paediatric care 15

4 Treatment of diabetes 16

4.1 Insulin treatment 16

4.2 Diet 16

4.3 Exercise 19

4.4 Blood glucose self-monitoring 21

5 Smoking among diabetic subjects 22

6 Alcohol use 23

7 Metabolic control 23

7.1 Hypoglycaemia and predictive factors 24

8 Lipids in diabetic adolescents 26

9 Development in adolescence 27

9.1 Weight and height 28

9.2 Psychological development 28

9.3 Psychological problems and diabetes 30

9.4 Eating disorders 32

10 Long-term complications 33
10.1 Nephropathy 33
10.2 Retinopathy 36
10.3 Neuropathy 38
11 Patient education 39
11.1 Development of patient education 39
11.2 Goals of diabetes patient education 40
11.3 Content of diabetes education 41
11.4 Educational philosophies 42
11.5 Traditional teaching and learning strategies used in diabetes education 46
11.6 A new education method, Tutorial Problem-Based Learning 47
11.7 Education interventions in diabetic adolescents 49
11.8 Evaluation of patient education in diabetic adolescents 50

AIMS OF THE PRESENT STUDY 51

PATIENTS 52
12 Inclusion of patients 52
13 Demographic data on the patients 53

STUDY DESIGN 55
14 Education 56
14.1 PBL method in practice 56
14.2 Individual counselling for the control group 58

METHODS 59
15 Questionnaires 59
16 Insulin injections 61
17 Diet 61
18 Exercise 61
19 Self-monitoring of blood glucose 62
20 Glycosylated haemoglobin HbA1c 62
21 Hypoglycaemia 62
22 Smoking 62

23 Alcohol use 62
24 Lipids 63
25 Blood pressure 63
26 Weight and height 63
27 Microalbuminuria 63
28 Retinopathy 64
29 Autonomic neuropathy 64

STATISTICAL METHODS 66

RESULTS 67
30 Feasibility of the PBL method in diabetes patient education 67
30.1 The PBL learning method in practice 67
30.2 Economy of the PBL method 70
31 Effect of education, comparison of methods 70
31.1 Diabetes-related knowledge questionnaires 70
31.2 Management of diabetes self-care 71
31.3 Independence in self-treatment 74
31.4 Glucose control 75
31.5 Hospitalisation 82
31.6 Attitudes and responsibility in daily care 83
31.7 Social function 87
31.8 Psychological health 89
31.9 Physical health 91

DISCUSSION 96
32 Patients 96
33 Methods 97
34 Education methods 98
34.1 The PBL method 98
34.2 Individual counselling 98
35 Feasibility of the PBL method 99

36 Effect of education 102
36.1 Management of daily diabetes care 102
36.2 Glucose control 106
36.3 Attitudes and responsibility of patients 110
36.4 Social function 112
36.5 Psychological health 114
36.6 Physical health 115
37 Achievement of educational objectives 119

SUMMARY AND CONCLUSIONS 120

ACKNOWLEDGEMENTS 122

REFERENCES 125

APPENDICES

Appendix 1 Education interventions among diabetic adolescents 143
Appendix 2 Learning topics and case examples for PBL sessions 147
Appendix 3 Questionnaire for demographic data and self-care practice . 152
Appendix 4 Knowledge test at the beginning of education 157
Appendix 5 Knowledge test at end 159
Appendix 6 Personality traits test, two example questions 160
Appendix 7 Depression inquiry (Beck and Beck) 163
Appendix 8 DQOL, quality of life inquiry 165
Appendix 9 Locus of control scale 169
Appendix 10 Questionnaire for parents 171
Appendix 11 Questionnaire for demographic data on healthy controls ... 174
Appendix 12 Quality of life inquiry for healthy controls 176
Appendix 13 Results of the personality traits test 177
Appendix 14 List of education material used in the current study 178

ABBREVIATIONS

AGE	Advanced glycated products
BMI	Body mass index (kg/m^2)
DQOL	Diabetes quality of life
DCCT	Diabetes Control and Complications Trial
E4	E4 phenotype
HbA1c	Glycohaemoglobin A1c
HDL	High-density lipoprotein
HLC	Health locus of control
IDDM	Insulin-dependent diabetes mellitus
LDL	Low-density lipoprotein
Lp(a)	Lipoprotein (a)
MHLC	Multidimensional health locus of control scale
MUFA	Monounsaturated fatty acids
PBL	Problem-based learning
SMBG	Self-monitoring of blood glucose
Tg	Triglyserides
VAS	Visual analogous scale
VLDL	Very-low-density lipoprotein
VO_{2max}	Maximal oxygen uptake

INTRODUCTION

Young diabetic patients constitute a challenging group in diabetes care. They often evince poor glucose control (Mortensen et al. 1997), incipient long-term complications (DCCT 1994) and psychological problems (Kovacs et al. 1997a). Transfer from paediatric to adult clinic care in adolescence severes long-term relationships formed with paediatric care personnel, in many cases adding to a teenager's difficulties. At the time of transfer, the patient's care is often, and at least partially, in the hands of the parents, and for such adolescents attainment of the necessary social maturation and independence in their diabetes self-care may be a difficult task.

Adolescence is a time when one's self-image is being constructed and diabetes self-care becomes integrated in daily life; it is the optimal time for diabetes education to instil a mastery over everyday care as well as an informed and appropriate attitude towards diabetes.

How young diabetic patients receive education regarding their disease varies widely from one case to the next. The greater part of diabetes education takes place during ordinary outpatient clinic visits and addresses either the whole family or the young patient alone depending on age. Camps have been a popular resource, accommodating adolescents in a relaxed atmosphere and providing an opportunity to interact with peers. However, only few young diabetic patients can participate in a camp and not all are motivated in adolescence attend a camp. In the DCCT study individual counselling was used in an intensive program in connection with clinic visits (DCCT 1994), but no reports are available of structured comprehensive education for adolescent diabetic patients at the phase of transfer from paediatric to adult clinic.

Problem-Based Learning is a constructive educational approach (Walton et al. 1989), which has not previously been employed in structured patient education. This learning method is based on the concept of new information being grounded on the knowledge already existing in the student's mind, the new and existing information being then synthesised into a body of integrated knowledge. In the Problem-Based Learning method learning is connected to the student's context and culture, and social interaction has an

important role (Rauste-von Wright and Wright 1995). Theoretically, the PBL method offers numerous advantages in diabetes patient education: everyday problems of diabetes care serve as learning material, group sessions afford patients a chance to interact with peers; there is an emphasis on personal responsibility in learning and decision-making; training in problem-solving enhances the skills and knowledge needed in daily diabetes self-care, which in turn helps foster independence and self-esteem in young diabetic patients. The PBL method in patient education makes possible a new direction, described as empowerment (European Diabetes Policy Group 1998, Ilanne-Parikka et al. 1999).

For evaluation of the effect of the PBL method in diabetes patient education during transfer from paediatric to adult medical care a structured education program was drawn up to be implemented in the context of ordinary clinic visits. The new method was compared with the conservative individual counselling presented in the Finnish diabetes recommendation (Koivisto et al. 1995).

REVIEW OF THE LITERATURE

1 PREVALENCE OF DIABETES IN ADOLESCENCE

In Finland the incidence and prevalence of Type 1 diabetes in children and adolescents are among the highest in the world. According to an epidemiological study by Tuomilehto and associates (1992), the overall annual incidence of childhood diabetes in Finland from 1987 to 1989 was about 35.2 per 100,000 subjects. It was higher in boys (38.4) than in girls (32.6). The incidence has been continually increasing; in 1997 it was 44.6 cases per 100,000 subjects (Åkerblom 1998). The total number of diabetic children under 15 in 1999 was 2,942 (The Finnish Health Insurance Institute 2000) among a total population of 5.1 million. In two out of three cases juvenile diabetes breaks out before the age of 25. Diabetes is second only to asthma among the chronic childhood diseases in Finland.

2 GOALS OF TREATMENT OF DIABETIC ADOLESCENTS

The goals of diabetes care are to enable good quality of life and to prevent acute and long-term complications. Glucose control near normoglycaemia can reduce and delay retinopathy, nephropathy and neuropathy (DCCT 1994). Goals specific to adolescent patients are normal growth and maturation, and independence in diabetes self-care including both social and psychological maturity and well-being (Koivisto et al. 1995). The bio-psychological model, which considers health in terms of personal experiences of general well-being and the capacity to perform expected roles and tasks in fulfilling one's health potential, is proposed as the objective of health promotion in adolescence (Perry and Jessor 1985).

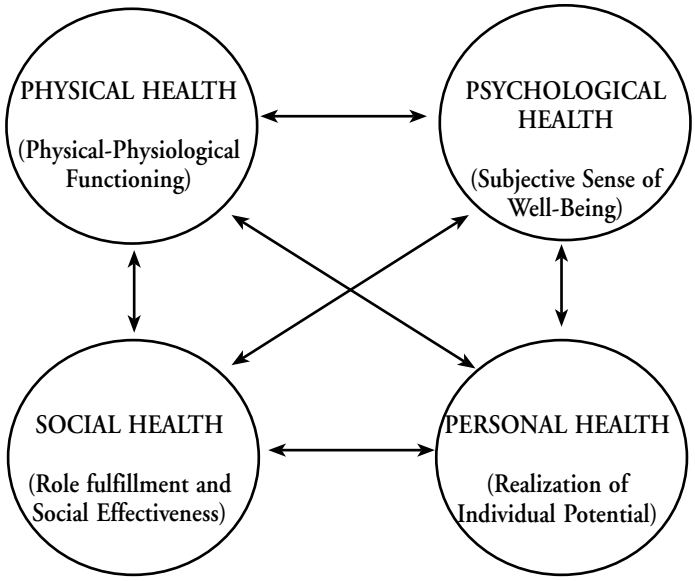

Figure 1. Four domains of health in adolescence

The authors Perry and Jessor suggest that our experience of health and well-being may be subdivided into four domains (Fig. 1). No one domain alone defines these aspects of an individual's life; rather these domains interact to provide the sense of a satisfactory quality of life which is the motivating force for every mature human being. Each domain is closely interconnected and intimately interrelated with the others. Adolescents will often participate in actions and behaviour promotive of a sense of well-being in one domain but creating risk in another. For example, a young diabetic subject may endanger his/her health by indulging in risk-laden behaviour such as emulation of non-diabetic peers. The goal in diabetes treatment should be a balance between the different domains and attainment of maximal well-being in all domains. Good physical health and glucose control near normal without complications, for example, will produce good psychological health, which in turn promotes adequate social function and thereby further enhances the sense of well-being.

3 Transfer from paediatric care

Our goals as caregivers should be to help individuals achieve their optimum potential and to minimise the effect of the disease on diabetic children and adolescent growth, development and social adjustment— help them lead lives as normal as possible.

There has been a great deal of controversy over the years as to who should care for the growing individual suffering from a chronic disease. Until their late adolescence young diabetic patients are usually attended by paediatricians and there has been no clear consensus on the appropriate age for transfer to adult care; the time of transfer varies in different hospitals and in different countries. Decisions on transfer are often complicated by the chronic nature of the disease, often long-term doctor-patient relationships, psycho-social problems, unresolved adolescent matters and the onset of the first diabetic complications which may make transfer difficult. For instance, Virtanen (1992) in a study of the diet of diabetic adolescents found that transfer of care between the ages of 15 to 18, when diabetic adolescents are usually referred to adult care, may be inappropriate because diet compliance is generally worsening at this age. In contrast, Orr and associates (1996) found that young diabetic patients' glucose control did not worsen after transfer to adult care, while Salmi and associates (1986) revealed that metabolic control improved significantly after transfer to adult care between the ages of 16.5 and 18.8 years.

In any case the transfer of diabetic adolescents from the paediatric department to adult medical care is considered an important step and recommendations on it have been published (Songini 1995, Vanelli et al. 1997). Thus in general transfer should, whenever possible, occur gradually and the adult clinic should be especially prepared to take over care of adolescent patients. For the most part young people with a chronic disease are infrequent patients at an adult clinic; moreover, internists are often unfamiliar with developmental issues in adolescents and unaware of the need to involve the patients' parents in the care. The role of the adult diabetologist in this situation is multiple, involving good diabetes management, an ability to establish relationships based on trust and understanding with adolescents, and a sense for pass from family-oriented care situation to one involving the adolescent only, all the while seeking to make these adolescents independent adults in the daily management of diabetes and reassuring them in their anxieties about their future as diabetics (Songini 1995). Ongoing collaboration between internists and paediatricians would be helpful, as would concentration of the care of diabetic adolescents among only a few caregivers who then would be able to gain experience in the treatment of young diabetic patients.

4 Treatment of diabetes

4.1 Insulin treatment

Blood glucose control in diabetic children deteriorates once they reach puberty. Poor dietary compliance, emotional instability and adolescent rebellion are contributing factors, but the onset of adolescence itself brings about a physiological reduction in insulin sensitivity occurring during puberty in the normal teens as well as in those with diabetes (Amiel et al. 1986). This results in a compensatory increase in basal and stimulated insulin secretion (Caprio et al. 1989). Growth, with increasing muscle mass, also requires an insulin increase. Rogers (1992), in his review describes the typical insulin dose range for patients in puberty as 1.0–1.2 U/kg/24h for males and 1.2–1.5 U/kg/24h for females. According to a Swedish study (Domargård et al. 1999) the insulin dose was 0.9 ± 0.2 U/kg in girls and 1.0 ± 0.2 U/kg in boys at a mean age of 18.2 ± 0.2 years. Insulin requirement varies according to the adolescent's developmental phase.

In the majority of studies of diabetic adolescents two or three injections of insulin are used. In the DCCT study (1994) the adolescent patients had an intensive insulin injection system entailing pump or multiple injection doses. The patients attained good glucose control, but the price was an enhanced risk of hypoglycaemia. However, a subsequent study of Boland and associates (1999) showed the opposite; the risk of hypoglycaemia was reduced by pump treatment regardless of metabolic control comparable with the DCCT study. In Finland a multiple injection insulin regimen is widely employed and patients are advised to seek the appropriate insulin doses by means of blood glucose measurements (Koivisto et al. 1995).

4.2 Diet

Goals of the diet

The objective of a proper diabetic diet is the same as that in diabetes treatment generally; good quality of life, good glycaemic control, prevention of acute and long-term complications, maintenance of normal weight, and guarantee of normal physical development in children (Diabetes and Nutrition Study Group, EASD 1995, Koivisto et al. 1995, The Finnish Diabetes Association 1999).

Diet recommendations

The dietary recommendations for diabetic subjects are very similar all over the world, differing only in minimal respects. The recommended portion of carbohydrates varies from 50 to 60 percent, fat from 25 to 35 percent, protein 15 per cent or less of total daily energy (European Diabetes Policy Group 1998, The Finnish Diabetes Association 1999). The diabetes diet diverges from the dietary recommendations for the general population only in its restriction on sugar from < 10% of total energy to 50 gr/day (Diabetes and Nutrition Study Group, EASD 1995, Koivisto et al. 1995).

The absorption of carbohydrates was enthusiastically studied in the 1980s in an effort to find diabetes-appropriate carbohydrate foods and to develop the concept of a glycaemic index. This index is defined as the increment area under the blood glucose response curve of a 50 g carbohydrate portion of a test food expressed as a percentage of the response to the same amount of carbohydrate from standard food taken by the same subject (FAO/WHO Expert Consultation 1997). Use of the glycaemic index in clinical care, however, remains controversial (Franz 1986). Glycaemic indices for individual foods have been established, but whether they can also be accurately applied to mixed meals, or can create a clinically significant difference in blood sugar, is not known. Omission of foods from the diet as having a high glycaemic index would not seem justified (FAO/WHO Expert Consultation 1997).

The ideal distribution of carbohydrates and fat has been a matter of controversy for many years. There is some support for a diet high in monounsaturated fatty acids (MUFA) instead of a high carbohydrate diet (Boctor and Jenkins 1990). A high-MUFA-diet lowers plasma cholesterol, but does not reduce HDL-cholesterol as does a low fat diet (Grundy 1986). There is also evidence that saturated fat increases insulin resistance (Storlien et al. 1996). In Finland rape seed oil could be appropriate for a high-MUFA diet.

A protein intake of about 15% of total energy is now recommended (Koivisto et al. 1995), the same as the recommendation for the population. In the past a protein intake of 20% or more was prescribed. Although it is not known whether a high protein intake will have a detrimental effect on the renal function of diabetic patients evincing no signs of nephropathy, it is recommended that protein intake should not exceed daily requirements. The recommended amount is 1 g / kg body weight (The Finnish Diabetes Association; the Nephropathy working group1996). There is evidence that in its early stages microalbuminuria may be reversed by a reduction in protein intake (Wiseman et al. 1987). The Finnish recommendation on daily protein for patients with incipient and established nephropathy is <1g/kg/body weight (Nephropathy working group of the Finnish Diabetes association1996).

A diet containing a substantial amount of fibre has been recommended because of its retarding effect on glucose absorption from the gastrointestinal tract (FDA 1999). In Finland rye bread has been the best source of fibre in the diabetes diet. The dietary fibre intake of diabetic adolescents, however, falls under the recommended average (Virtanen 1992).

Energy requirements involve what is needed to achieve and maintain normal growth. Identification of the proper energy requirements can be challenging since energy needs may vary substantially, especially during growth spurts or as the activity level varies. According to the recommendation (European Diabetes Policy Group 1998, American Diabetes Association 1997)) one may eat in line with natural appetite and energy needs. Some authors suggest that external regulation of energy intake by health professionals as opposed to the individual's internal regulation via appetite is highly presumptuous and constitutes a major reason for poor diet compliance (Nuttall 1987).

Diet compliance

Diabetic patients have individual diet schedules, but among adolescents compliance with prescriptions is often poor. Prevention of complications thirty years into the future would seem to be too distant a goal for many teenagers to respond to, and if they are pressed to comply, they may adopt defensive strategies which bring them into conflict with parents and professionals. Tattershall (1987) has drawn attention to the difficulties of adolescent patients: "These young people have already been made to feel different from their peer group. Dietary advice should be sensitive and deviate as little as possible from customary habits". Jones and colleagues (2000) have documented the increasing frequency of eating disorders in young diabetic women when compared with healthy controls.

According to studies by Schmidt and associates (1992) and Virtanen (1992), adolescent diabetic patients and healthy controls exceed their prescribed energy intake, the additional energy deriving from fat sources. Intra-individual variation in energy intake, carbohydrate, protein and fat level increased with age but was less pronounced among diabetic patients compared to controls.

The DCCT study found no differences in energy and nutrient intakes between intensive and standard treatment groups. The patients were interviewed one and two years after randomisation (Schmidt et al. 1994).

Schlundt and colleagues (1996) found in a summer camp that dietary self-efficacy was improved among young people with diabetes by problem-solving group sessions led by a registered diet therapist instructing them in effective ways to solve dietary problems.

Diet and glycaemic control

Virtanen (1992) found that good glycaemic control was associated with high intra-individual variations in energy intake, whereas Schmidt and associates (1992) could reveal no relationship between glycaemic control and compliance with dietary prescriptions. In the study by Christensen and associates (1983) it was documented that patients who had the poorest control of their diabetes also had the greatest number of deviations from their prescribed food exchanges, while in the study of treatment domains by Burroughs and colleagues (1993), dietary adherence was most closely associated with metabolic control.

Most diet surveys have involved patients using conservative insulin treatment consisting of two or three daily insulin injections. As a result of multiple injection therapy, compliance with prescribed diet schedules has received less emphasis and a patient's ability to adjust diet and insulin according to daily activity level is considered more important. The patient's ability to make proper adjustments is measured by glycaemic control and weight, which are regularly monitored during ambulatory visits (Koivisto et al. 1995, FDA 1999). From a psychological point of view multiple injection therapy may be helpful; patients may eat according to their appetite and likings. This "freedom" may at times, however, and especially among adolescents with increased appetite, lead to uncontrolled eating and neglect of blood glucose measurements and proper insulin doses, glucose control totally deteriorating. However, eating is a satisfying pleasure and the diet should be a compromise between recommendations and individual eating habits.

4.3 Exercise

Exercise with its therapeutically beneficial effect on glucose control is considered one of the cornerstones of diabetes treatment and is emphasised in patient education. Arslanian and associates (1990) found that glycaemic control and physical fitness explained 73 percent of the variation in insulin resistance in diabetic adolescents. The authors suggest that modifying aerobic fitness via physical training which simultaneously improves glycaemic control might normalise insulin action in adolescents with IDDM.

The effects of exercise on insulin-dependent diabetes depend on the level of insulin concentration during exercise. If there is insulin excess—for example the insulin dose is high or insulin is injected prior to exercise involving the legs, thus increasing insulin absorption (Koivisto et al. 1978) – hepatic glucose production is inhibited and the antilipolytic effects of insulin prevent the mobilisation of free fatty acids from adipose tissue stores. In this situation, muscle glucose utilisation being markedly augmented,

the failure of hepatic glucose production to increase results in a rapid fall in plasma glucose concentration and thus hypoglycaemia.

On the other hand, insulin deficiency in the blood has a consequence of an exaggerated increase in hepatic glucose production and causes hyperglycaemia, since with insulin deficiency muscle glucose utilisation becomes impaired. With an adequate insulin concentration, the result is therapeutically beneficial (Berger et al. 1977).

Hypoglycaemia with exercise

Late-onset hypoglycaemia is the most prominent problem with exercise and diabetes. There may be several contributing factors. For instance, hypoglycaemia may be associated with muscle and/or liver glycogen depletion consequent upon unusually intense or prolonged exercise. The patient's own management of his/her condition, including the timing and/or amount of food, exercise and insulin may likewise be a reason of hypoglycaemia. MacDonald (1987) investigated the prevalence and timing of late-onset hypoglycaemia in 300 diabetic adolescents and found its frequency to be 16 percent over a 2-year study period. The average time of onset of hypoglycaemia was 10 h after exercise. The intensity and duration of the exercise associated with delayed hypoglycaemia was reported to be exceptional to each patient.

The need for frequent self-monitoring of glucose is emphasised to diabetic patients involved in exercise in order to help them adjust the components of their treatment. In a study of adolescent diabetic boys by McNiven Temple and associates (1995) it was shown that individual blood glucose responses to prolonged moderate-intensity exercise are reliable and repeatable when pre-exercise meal, exercise and insulin regimens are kept constant.

Beneficial effects of exercise

Exercise has beneficial effects on the lipid profile; in healthy adolescents physical activity, independent of their dietary habits, reduces total and LDL cholesterol and increases HDL cholesterol except in the apo E phenotype E4/4 (Taimela et al. 1996). According to a study by Austin and colleagues (1993) diabetic adolescents' physical fitness correlated inversely with HbA1, insulin doses, cholesterol, LDL, Tgs and Lp(a), but did not correlate with HDL, which in turn correlated inversely with BMI. Diabetic subjects had lower VO_2max than controls.

Huttunen and colleagues (1989) studied the effect of exercise in diabetic patients aged 8 to 17 and found that one hour of weekly exercise during a three-month period

improved physical fitness significantly but that glucose control deteriorated as assessed by HbA1. Older diabetic adolescents evinced poorer metabolic control and also more often neglected to participate in weekly sessions compared to younger. Clinically, it has been suspected that exercise may have a deleterious effect on diabetic retinopathy. However, no association between physical activity during college years and proliferative retinopathy was found in insulin-dependent diabetes (LaPorte 1986).

4.4 Blood glucose self-monitoring

Maximal self-care is a commonly stated goal in the modern treatment of diabetes. For children and adolescents this requires the gradual establishment of a blood glucose self-monitoring (SMBG) regimen. It has been estimated that beginning at ages nine through twelve a child is capable of performing blood glucose testing reliably (Wysocki et al. 1992a). In the study in question parents reported that children and adolescents with IDDM mastered self-care skills more rapidly than had been predicted by professionals, the difference being approximately one year.

On the other hand, several studies of adolescents have revealed problems in blood glucose self-monitoring. According to the findings of Wing and associates (1986), only 48 percent of diabetic adolescents measured their blood glucose accurately. The criterion for accuracy was an error less than twenty per cent of the corresponding laboratory value. Delamater and associates (1989) found 75.5 to 87.9 per cent of measures accurate depending on the use of a visually readable strip or a meter. It may be assumed that during the last few years accuracy in blood glucose self-monitoring has improved with the development of devices whereby the timing of the procedure and the blood drop are adjusted by the meter itself.

In the DCCT study, patients were instructed to perform four daily blood sugar measurements as well as two additional night measurements once a week (DCCT 1995a).

Adolescents' adherence to SMBG has been widely studied. Most studies reveal that neglect is quite common; for example, tests are not made or are merely recorded as made (Delamater et al. 1989, Wysocki et al. 1989). The likelihood of cheating increases as patients move from preadolescence to young adulthood (Ernould et al. 1982). Only Snyder and colleagues (1992) found good compliance and no signs of fabricated test results. However, the adolescent diabetic patients selected for the study in question were highly motivated. In none of the studies was a correlation found between frequency of self-monitoring of blood glucose and HbA1c. In the study of Evans and associates (1999) frequency of uptake of reagent strips for SMBG associated with glycaemic control. Nonetheless, adolescents and young adults were those who neglected their SMBG most.

The data obtained through blood glucose self-monitoring are not used maximally by families with a diabetic adolescent. According to Wysocki and colleagues (1992b), fifty-five per cent of families used blood glucose self-monitoring data for the correction of hypoglycaemia and fifteen per cent for dietary adjustments.

5 SMOKING AMONG DIABETIC SUBJECTS

Smoking among young people is wide spread; of young men aged 21 to 22, thirty per cent have been reported to smoke (Valtonen et al. 1984), of adolescents of both sexes aged 14 to 16 twenty-nine per cent smoke daily (Rimpelä et al. 1996a). Kokkonen and Paavilainen (1993) found that fifty percent of diabetic men aged 27 to 28 in the Oulu area smoked and that the smoking rate for their female counterparts was thirty-three percent, which agreed with the frequency rate among non-diabetic controls. Poor glucose control was associated with smoking.

In the Eurodiab IDDM Complications Study (Chaturvedi et al. 1995), thirty-five per cent of men and twenty-nine per cent of women were found to be smokers. Smoking was associated with poorer glycaemic control as compared with non-smokers. Ex-smokers had levels of glucose control equivalent to non-smokers. Active smokers had a higher prevalence of microalbuminuria as compared with those who never smoked. Male ex-smokers had a higher prevalence of macroalbuminuria and a similar prevalence of microalbuminuria as compared with those who never smoked. The authors hypothesised that the deleterious effects of smoking on microvascular complications may not persist once smoking is discontinued. The progression of albuminuria is reduced in those who stop smoking (Chase et al. 1991, Sawicki et al. 1994).

The association of retinopathy with smoking is controversial. In a study by Chase and colleagues (1991) no association of diabetic retinopathy with smoking was found in diabetic patients aged 19 to 23, but according to Chaturvedi and associates (1995) the prevalence of retinopathy in men was greater in active and ex-smokers compared with those who never smoked.

The mechanisms behind this negative effect of smoking are thought to be multiple. Smoking has stimulatory effects on insulin antagonists such as cortisol and adrenaline, which cause insulin resistance and hyper-insulinaemia (Facchini et al. 1992) thus leading to poor glucose control. Smokers have poorer glycaemic control compared with non-smokers and it is suggested that much of the implication of smoking in microvascular complications consists in its association with glycaemic control (Chaturvedi et al. 1995). Despite the evidence that smoking causes health complications in people with

IDDM, the results of antismoking education have been poor (Kokkonen and Paavilainen 1993).

6 Alcohol use

In Finland alcohol use among young people has recently been documented by Rimpelä (1996b) in a population-based study. Among healthy adolescents aged 14 to 16, eighty per cent used alcohol. In the United States 40 to 49 per cent of young people use alcohol regularly (Berg-Kelly 1995). In a survey of 100 American diabetic adolescents approximately 50 per cent had at least tried alcohol and 26 per cent reported some level of ongoing use (Glasgow et al. 1991). There was no difference in metabolic control or treatment compliance as estimated by physicians between those who used alcohol and those who did not. In a Finnish survey diabetic adolescent males seldom used alcohol, females not at all (Virtanen 1992).

Hypoglycaemia is the most disadvantageous effect of alcohol use with diabetes. Alcohol reduces gluconeogenesis in the liver (Puhakainen et al. 1991). The danger of heavy uncontrolled drinking is emphasised in a study by Borch-Johnsen and colleagues (1993) which examined causes of death in diabetic patients. In deaths involving hypoglycaemia, ketoacidosis or unknown cause, chronic alcohol use or alcohol intoxication was a cofactor in 50 per cent of cases. Alcohol was involved in only 16 per cent of deaths from natural causes.

The data concerning the effect of alcohol on long-term diabetic complications are controversial. It is assumed that the toxic effect of alcohol on the nerves, together with hyperglycaemia, accelerates the development of neuropathy. Among patients who are active drinkers, peripheral neuropathy is three times as likely compared with those who seldom use alcohol (McCulloch et al. 1980). However, in the Eurodiab IDDM Complications Study (Tesfaye et al. 1996) no association emerged between alcohol consumption and neuropathy. Alcohol consumption in moderation does not appear to affect the occurrence of diabetic retinopathy (Moss et al. 1994).

7 Metabolic control

Several studies have demonstrated the significance of good metabolic control in preventing microangiopathic complications in diabetes (DCCT 1993, Reichard et al. 1993, Bangstad et al. 1994). Good glycaemic control, especially during adolescence, is important in that there are indications that puberty accelerates diabetic microvascular compli-

cations (Kostraba et al. 1989, Janner et al. 1994, Kokkonen et al. 1994a). However, severe hypoglycaemia may be an adverse effect of strict glycaemic control (DCCT 1991), although an opposite result is also to be found; severe hypoglycaemias decreased with pump treatment (Boland et al. 1999).

Several studies have shown the metabolic control of adolescent diabetic patients to be poor. In an epidemiologic study by Mortensen and group (1997), the glycohaemoglobin HbA1c of diabetic adolescents was found to be high, higher in girls than in boys, and only increasing with age and duration of diabetes. According to Olsen and associates (1999) only 11% of young Danish patients had good diabetes control. In Finland Käär (1983), Virtanen (1992), and Pietiläinen and colleagues (1995) obtained similar results. In addition, in the DCCT study baseline metabolic control of adolescent diabetic patients was unsatisfactory, despite high selectivity of the material. HbA1c was 9.2 to 9.3 per cent in the primary prevention cohort and 9.8 to 10.1 per cent in the secondary intervention group. Girls had poorer metabolic control than boys (DCCT 1994). The values were higher than corresponding values in adult subjects and also remained at a higher level during the study.

In addition to neglect of diabetes self care there are other reasons for unsatisfactory metabolic control during adolescence. One is the insulin resistance associated with adolescent development (Amiel et al. 1986). Growth hormone hypersecretion is typical in IDDM during adolescence and correlates positively with HbA1c (Dunger et al. 1991).

Insulin requirements increase during the early morning hours causing pre-breakfast hyperglycaemia in some patients with IDDM. This is known as the "dawn phenomenon." It has been suggested that nocturnal growth hormone secretion is the reason (Edge et al. 1990a). Due to increased growth hormone secretion, the dawn phenomenon may became more pronounced during puberty. On the other hand, Arslanian and colleagues (1992) showed that the insulin clearance rate increased in diabetic adolescents during the early morning at the same time as the growth hormone level was dropping. To blunt the dawn phenomenon, it is recommended that intermediate-acting insulin be administered at bed time.

7.1 Hypoglycaemia

Prevalence and predictive factors

Hypoglycaemia is classified as mild if the symptoms disappear or are treatable by the patient him/herself, and severe when there is a need for assistance (grade III) and/or loss

of consciousness with or without convulsions (grade IV) (Gale and Tattershall 1990). Hypoglycaemia is the most frequent acute complication of insulin-dependent diabetes (Cryer et al. 1989). Mild symptomatic hypoglycaemia is often considered an inevitable consequence of good diabetes control. Intensified insulin therapy using multiple daily injections or continuous subcutaneous insulin infusion has been found to increase the frequency of severe hypoglycaemia (DCCT 1991), also in diabetic children (Egger et al. 1991). In the DCCT (1991) 77 per cent of 714 hypoglycaemic episodes occurred in intensively treated subjects. The frequency was threefold that found in therapy involving one or two injections. Severe hypoglycaemia occurred most often during sleep. The predictive factors for severe hypoglycaemia were a history of the disorder, long duration of IDDM, high baseline HbA1c and low recent HbA1c. In a study of Limbert and associates (1993) 44 per cent of adolescents with IDDM had severe hypoglycaemic attacks, of which 50 per cent were without antecedent symptoms. The frequency is higher than that found in an earlier study (Daneman et al. 1989). The causative factors underlying hypoglycaemia in a study of Limbert and associates (1993) were identified in 50 per cent of hypoglycaemic attacks and ranged from strenuous physical exercise to insufficient or delayed food intake and to inappropriate insulin administration. Alcohol was the major contributor in only two cases. The authors concluded that continued education of patients should help to reduce the risk of severe hypoglycaemia. Norfeldt and Ludvigsson (1997) came to the same conclusion in a study in which they demonstrated that multiple injection insulin therapy combined with adequate self-control and active education did not increase hypoglycaemia, even when a HbA1c near normoglycaemia was attained. Boland and colleagues (1999) found continuous subcutaneous insulin infusion to reduce the risk of hypoglycaemia among adolescent patients in spite of decreasing HbA1c. In a Finnish study by Tupola and colleagues (1998a) the incidence of severe hypoglycaemia in diabetic adolescents was low, 3.1/100 patient years, which the authors concluded to be attributable to multiple-dose insulin therapy.

Lack of awareness of hypoglycaemia

Strict glycaemic control may result in defective glucose counter-regulatory hormone responses and a diminished perception or lack of awareness of hypoglycaemia and thereby increase the risk of hypoglycaemia (Amiel et al. 1991 and 1987, Hoffman et al. 1991, Mokan et al. 1994). It has been shown that neuroendocrine counter-regulation and hypoglycaemic symptom awareness occurring as a consequence of hypoglycaemic episodes may be improved by as short as a two-day interval of strict avoidance of hypoglycaemia (Dagogo-Jack et al. 1994, Lingenfelser et al. 1995).

On the other hand, poor metabolic control might influence the hormonal response to hypoglycaemia in diabetic patients by raising the plasma glucose level at which counter-regulatory responses occur, thereby making good glucose control difficult to maintain. Jones and associates (1991) found in diabetic adolescents with poor glucose control that epinephrine was released at a higher plasma glucose level than in non-diabetic controls.

Reported symptoms of hypoglycaemia in children are a coalescence of neuroglycopaenic and autonomic symptoms (McCrimmon et al. 1995) as opposed to adults who can distinguish between these types of symptoms (Deary et al. 1993). Tupola and Rajantie (1998b) found weakness, tremor, hunger and drowsiness to be the most common symptoms of hypoglycaemia in diabetic adolescents. Of all dominant symptoms 39% were classified as autonomic, 20% neuroglycopaenic and 41% non-specific.

There have been attempts to enhance blood glucose awareness in adolescents (Freund et al. 1986). Nurick and Johnson (1991) found that the basic level of blood glucose awareness in adolescent diabetic patients was low and that subsequent training resulted in only a 23 per cent increase in awareness. Blood sugar estimations were misleading; the same symptom predicted hyperglycaemia for one patient and hypoglycaemia for another. Only one symptom, feeling shaky, was predictive of hypoglycaemia for more than half of the patients.

Northam (1992) found no association between neuropsychological dysfunction and major metabolic crises, for example hypoglycaemic attacks, in adolescent diabetics. These results agree with those of the DCCT study (1996a) in which no correlation was seen between neuropsychological function and recurrent hypoglycaemia in insulin-dependent diabetic patients.

Wredling and colleagues (1992) found the psychosocial disposition of diabetic patients prone to recurrent episodes of hypoglycaemia to be different from those less prone; their anxiety level was increased and their sense of well-being diminished.

8 Lipids in diabetic adolescents

There have been few investigations of serum lipids in diabetic adolescents. At the Pittsburgh Diabetes Clinic, cardiovascular risk factors were evaluated in 140 diabetic adolescents (Cruickhanks et al. 1985). Their siblings served as controls. The values in girls were significantly higher compared with boys in both groups, but there was no difference between diabetic subjects and controls. No association was found between lipids and metabolic control. HDL-cholesterol fell in both groups to the puberty stage of Tanner 5.

In the DCCT study (1994) total cholesterol values were significantly higher in conventionally than in intensively treated diabetic adolescents by the end of the study, but there were no significant differences in low-density lipoprotein-cholesterol or in high-density lipoprotein values between conventional- and intensive-treatment groups. In multiple regression analysis total cholesterol and LDL cholesterol correlated significantly positively with HbA1c.

In a comparison of lipid values in the DCCT study with those obtained by similar methods in the Lipid Research Clinics prevalence study of non-diabetic individuals, no difference emerged except in young diabetic females aged 15–19 yr, whose lipid values in all categories were significantly more atherogenic than the those in non-diabetic women of the same age. The correlation between lipid levels and dietary variables was weak, the most prominent being that between high calories and quantities of carbohydrates and low total cholesterol and low HDL-cholesterol. A drinking history was the only important factor correlating positively with HDL cholesterol (DCCT 1992).

In a study by Virtanen and associates (1993) Finnish diabetic adolescents had lower total cholesterol compared with the DCCT study, but higher than in the Pittsburgh study. Total cholesterol and triglycerides correlated positively with poor metabolic control (HbA1≥10.5 per cent). Total and LDL-cholesterol were associated with the intake of saturated fat.

In a population-based study of healthy 15-year-old young people in eastern Finland (Vartiainen et al. 1996) the average total cholesterol in both girls and boys was lower compared with adolescent diabetics (Virtanen 1993). The values in healthy adolescents have decreased linearly since 1984, the most important reason for this development being the decreased intake of saturated fat found in dairy products.

9 Development in adolescence

Adolescence is commonly defined as the period between childhood and adulthood, usually between the ages of 11 and 21 years (Joffe 2000). It is a period of great emotional and physical turmoil, encompassing puberty, school examinations, leaving home and starting work or higher education. There is an allegory of "rebirth from the womb of the family" during adolescence. Under normal circumstances this process may be painful for even the healthiest individuals, and for a young person chronically ill even more so. Among other things, coping with the demands of self-care of diabetes may become a formidable task. During adolescence there is often conflict with parents, with the young resisting adult authority, along with mood disruptions and a greater proneness to risky behaviour.

9.1 Weight and height

Weight gain during puberty accounts for approximately 40 per cent of the ultimate adult weight. This weight gain is due to an increase in both subcutaneous fat and muscle mass. In several studies the weight of diabetic children has been greater than that of controls, and this deviation has only increased by the time of the follow up. Both Finnish (Pietiläinen et al. 1995) and Swedish (Domargård et al. 1999) diabetic girls are more likely to be overweight than healthy control girls. The authors of both reports conclude that more effective prevention of obesity is needed in the treatment of diabetes. In the DCCT study (1994) intensive treatment had no effect on the adult height of adolescents, but did cause a greater gain in weight and a twofold increase in the risk of becoming overweight when compared to conventional treatment. Weight loss for diabetics is difficult. Thomas-Dobersen and colleagues (1993) describe an intervention program for obese adolescents with IDDM. The program comprised 14 weekly sessions in which subjects and their parents participated in separate groups. The weight loss by the end of follow-up of 15 months later was found to be only 3 per cent and did not differ from the result in the conservative treatment group, although self-esteem was significantly improved in the intervention group.

Since the discovery of insulin, height and its association with glucose control in diabetes has been under examination; impaired longitudinal growth in children with diabetes was a common observation during the earliest decades of research. Wise and associates (1992) found that glycohaemoglobin level and growth retardation correlated in diabetic children who were pre-pubertal or in the early stages of puberty, whereas children in late puberty appeared less sensitive to the growth-suppressive effects of hyperglycaemia, except if they had very poor metabolic control, GHbA1 >16 per cent. Danne and colleagues (1997) found both pre- and post-pubertal glycaemic control to be of importance for the diabetes-related growth deficit.

9.2 Psychological development

The ultimate goal in adolescence is to attain maturity both physically and psychologically. The maturational growth factors in adolescence, also envisaged as psychological tasks, are peculiar to modern Western society. For the most part these factors are independent of the physical development of puberty (Slap 1986).

1. Independence and dependence

Early adolescence is characterised by behaviours and activities which promote in the teenager a sense of detachment from previously accepted family norms. Often this is more an emotional divergence of interest than a desire for physical emancipation from the family. A teen's time and interest are increasingly committed to the peer group. Conflict, if present, usually centres on restrictions imposed by the family. Feelings of ambivalence predominate in most interpersonal interactions. Often self-awareness is high, and parents are abandoned as authority figures, something which also takes place with adolescents in diabetes care.

2. Peer group acceptance

The manifest modes of behaviour of teenagers are those which promote acceptance from their peers and may involve values differing from those held by their families. Neglecting a healthy diet may happen among adolescent girls and boys with IDDM. Frank conflict and rebellion may be manifested as a result of discord between peer-group and family values.

Throughout childhood, satisfactory metabolic control is often maintained by virtue of well-structured home and school environments. However, this structure may deteriorate as the child enters adolescence and begins spending more time with peers and less time under the parents' watchful eye. Control of the diabetes regimen usually passes into the hands of adolescents who may not be ready to handle this responsibility effectively. In order to maintain good metabolic control, the adolescent must accomplish a complicated balancing act of diet, insulin dosage and exercise in addition to dealing with all the emotional changes which accompany adolescence.

3. Life goals

With the approach of high school graduation, an increased pressure is felt to make important life plans and commitments. This may further serve to compound incompletely resolved earlier tasks; the competing claims of independence and dependence, peer-group acceptance and sexuality may manifest themselves in a lowering of school achievement and neglect of diabetes self-care.

4. Sexuality and intimacy

Physical developmental dimorphism is complete by middle to late adolescence and social behaviour and dress only accentuate these differences. With an increasing sense of the self as distinct from others, the late adolescent or young adult yearns for intimacy and is able to create a relationship with the other gender.

5. Physical emancipation

The desire to separate oneself physically from the family of origin in order to build a nest of one's own involves one of the later tasks of adolescence. In the economy of the 1990s, however, this task was often difficult to fulfil. Separation from parents may be especially difficult for diabetic adolescents because their parents are so often overprotective and practically involved in the treatment of their children. Kokkonen and colleagues (1994b) showed that diabetic subjects aged 19 to 25 more often lived in the same household with their parents and had more difficulties in separating from their parents than did their non-diabetic controls. They were also more often unmarried compared with healthy controls.

9.3 Psychological problems and diabetes

Insulin-dependent diabetes has been found to be a risk factor underlying adolescent psychiatric disorders. Kovacs and associates (1997a) followed young diabetic patients for 10 years and found 47.6 per cent of the cohort to develop a psychiatric disorder during that period. Especially young diabetic women seemed to be disposed to recurrent depression, of which less than half was diagnosed and treated. Blanz and colleagues (1993) investigated adolescents with IDDM aged 17 to 19 and discovered an overall rate of psychiatric disorders of 33.3 per cent vs. 9.7 per cent for non-diabetic controls. This rate was similar in both genders. The diabetic adolescents suffered from significantly more introversive symptoms than their healthy counterparts, especially somatic symptoms, sleeping disturbances, compulsions and depressive moods. They also had less cohesion and more conflicts with their families. No correlation was detected between the severity of psychiatric disorders and metabolic control. On the other hand Ryden and associates (1994) reported more psychiatric symptoms in diabetic adolescents and young adults with poor metabolic control compared with those with better control. Both poor glucose control and psychological disturbances are more marked the longer young patients have had IDDM (Kovacs et al. 1997b). In the Pittsburgh epide-

miology of diabetes complications study (Lloyd et al. 1992a) higher depression scores were related to the presence of long-term diabetic complications.

There are case reports of diabetic youths attempting suicide through an overdose of insulin (Kaminer 1988). In the international evaluation of cause-specific mortality in IDDM (Diabetes Epidemiology Research International Mortality Study Group 1991), a larger percentage of young diabetic adults were found to have died as a result of suicide in Finland compared with other countries. In Finland young men have a higher suicide rate compared with other Nordic countries (Retterstol 1992). Goldston and colleagues (1997) found suicidal thoughts and serious non-compliance in diabetes treatment to be associated among teenagers.

A small percentage of young patients with IDDM experience profound difficulties in maintaining glycaemic control. Their lives are constantly disrupted by either recurrent hypoglycaemia or recurrent ketoacidosis. They may be considered to have "brittle diabetes" (Tattersall 1985). Although the underlying causes are thought to be organic, psychosocial factors which act to exacerbate and perpetuate the disorder would also seem to be present. Psychoanalytic treatment has proved effective in improving poor glucose control in diabetic adolescents for as long as one year after the intervention (Moran et al. 1991).

The demands of tight metabolic control are suspected to have a significant impact on young diabetic subjects and to give rise to psychological problems in early adulthood. Pless and associates (1988) found no statistically significant relationship between these problems and physician's desired levels of control. In the DCCT study, no difference in perceived quality of life was found to exist between the intensive treatment group and the control group (DCCT 1996b). Thus efforts to achieve good metabolic control during childhood may not be followed by psychosocial problems later in life. However, Lloyd and colleagues (1992b) found young adult diabetic subjects to be significantly less likely to feel academically competent in comparison with their healthy matched controls despite similar academic achievements. More than half reported that they had experienced a variety of difficulties at school. This is thought to be associated with reduced self-esteem. Jacobson and colleagues (1997a) found no serious problems in young IDDM patients in forming social relationships during the transition to young adulthood in their ten-year follow-up study. However, the young diabetics had a lower level of trust and intimacy within love relationships compared with healthy controls, which was in harmony with the lowered self-evaluation detected in the same study.

Moreover, the criteria for disturbances are somewhat varied. Improved communications between diabetologists and psychologists have been suggested as a means of further development of psychological investigation in diabetes (Rubin and Peyrot 1992).

9.4 Eating disorders

Eating disorders are frequently encountered in diabetic adolescent girls and young women, but whether or not a specific association exists between these two disorders remains controversial. Some studies have suggested that an increased incidence of eating disorders exists in young women with IDDM (Vila et al. 1995, Jones et al. 2000) whereas others have detected no such an increase (Peveler et al. 1992, Striegel-Moore et al. 1992). These discrepancies may be attributable to methodological differences in study design, measurement tools, and the small size of study groups. Diagnostic criteria also vary widely.

Nielsen and colleagues (1987) found a 0.02 per cent prevalence of IDDM patients with eating disorders among patients treated at the Psychiatric and Child Psychiatric clinics of Copenhagen's Rikshospital between 1960 and 1984. The prevalence was estimated to be six times higher than expected. A more common research approach has been to assess eating disorders in patients with IDDM. Peveler and associates (1992) diagnosed clinical eating disorders according to DSM-III-R criteria in 9 per cent of adolescent girls with IDDM as opposed to 6 per cent of their control group. In a study by Jones and colleagues (2000), 10 per cent of adolescent girls with IDDM had eating disorders versus 4 per cent of healthy girls. Polloc and colleagues (1995) tracked young diabetic patients for approximately 9 years and discovered DSM-III eating disorder in 3.8 per cent. Including the cases with DSM-III eating disorder, altogether 11.4 per cent of the patients had eating problems. Those with eating problems had a significantly higher rate of psychiatric disorders than the rest of the sample. Furthermore, every patient who had an eating problem was non-compliant with medical treatment as compared with 36 per cent of the remaining youths. Insulin-omission is common (Polonsky et al. 1994, Rydall et al. (1997). Other weight-reducing methods practised by adolescent diabetic girls are dieting, self-induced vomiting and extreme exercise. Those with an eating disorder are also less compliant with other aspects of IDDM management and have poorer metabolic control and lipid disorders (Affenito et al. 1997a and b, Jones et al. 2000) and more diabetes complications compared with insulin non-omitters (Polonsky 1994, Rydall et al. (1997). Disordered eating behaviour seems to be persistent in young women with IDDM (Rydall et al. 1997).

Rodin and Daneman (1992) suggested in their review several hypotheses by way of explaining eating disorders among insulin-dependent diabetics. For example, IDDM may impair development of the ego and in this way predispose patients to eating disorders. Food is a concentric factor in diabetic treatment by reason of the need for chronic dietary restraint. The implementation of insulin treatment induces weight gain which may trigger increased dissatisfaction with the body and lead to a cycle of dieting and

binge-eating. On the other hand, insulin-omission is a potent means of achieving weight loss. Metabolic factors, hyperglycaemia, peripheral hyperinsulinemia and the like may in themselves precipitate eating pathology. Diabetes may also affect parental attitudes and parent-child interactions and in this way lead to eating disorders. In a study by Maharaj and colleagues (1998) eating disorders were associated with poor communication with parents, and family environments were perceived to be conflictual and inadequate in support.

10 LONG-TERM COMPLICATIONS

10.1 Nephropathy

Microalbuminuria

Microalbuminuria is a sign of incipient nephropathy in IDDM (Viberti et al. 1982). Approximately 30 per cent of patients with insulin-dependent diabetes will develop diabetic nephropathy (Kofoed-Enevoldsen et al. 1987). The risk of premature death from renal or cardiovascular disease is greatly increased in those with diabetic nephropathy (Borch-Johnsen et al. 1985).

Definition

The definition of microalbuminuria has varied. Measurement of the albumin excretion rate in a timed urine collection should be regarded as the golden standard (Mogensen et al. 1985). Timed urine collections, however, often cumbersome for patients, are subject to inaccuracies in timing and associated with poor compliance. The method used varies in different studies. Collections gathered during night sleep, over 24 hours, and random samples have all been used (Microalbuminuria Collaborative Study Group 1992, Widstam-Attorps et Berg 1992, Lawson et al. 1996). Also used is the ratio of urine albumin/creatinine (Marshall 1991). The established consensus definition of persistent microalbuminuria is an albumin excretion of 20-200 ug/min in at least two out of three consecutive timed urine collections (Mogensen 1985). This is also included in the Finnish Recommendation (The Finnish Diabetes Association, Nephropathy Working Group 1996). In healthy subjects the excretion rate is 5–15 ug/min (Viberti et Wiseman 1986).

Prevalence among diabetic adolescents

According to Quattrin and associates (1995), the frequency of microalbuminuria was 17.8 per cent in an adolescent diabetic population, agreeing with the frequency of 15 per cent at Huddinge University Hospital (Widstam-Attorps (1992).

Intermittent microalbuminuria

Transient episodes of microalbuminuria have been observed in patients who have subsequently developed persistent microalbuminuria as well as in those who have not (Cooper et al. 1989). Bach and colleagues (1993) discovered during their follow-up 6.6 years later that 12.8 percent of those diabetics who developed persistent microalbuminuria had positive microalbumin measurements compared to 5.5 per cent of those who remained normoalbuminuric.

Risk factors for nephropathy

Though the precise mechanisms involved in the pathogenesis of microalbuminuria have not been established, several factors contributing to the development of condition are known.

Hypertension: A large number of studies have documented elevated blood pressure in microalbuminuric insulin-dependent diabetic patients compared with macthed normoalbuminuric patients (Microalbuminuria Collaborative Group 1992, Quattrin et al. 1995). It remains unresolved whether the rise in blood pressure precedes or parallels microalbuminuria. Barzilay and colleagues (1992) found that type I diabetic patients who suffered from nephropathy and hypertension more frequently already had a positive family history of hypertension and a higher mean arterial pressure during adolescence and early adulthood than their normoalbuminuric controls.

Hyperglycaemia: Barzilay and colleagues (1992) also showed that patients with nephropathy had significantly poorer glycaemic control during their first 12 years of diabetes than their controls without albuminuria. During the past few years evidence has accumulated of a correlation between hyperglycaemia and diabetic nephropathy (Bangstad et al. 1989, DCCT 1994, Krolewski et al. 1995). The DCCT study demonstrated that glucose control near normoglycaemia retarded and prevented the development of nephropathy. Bangstad and associates (1994) found that good glycaemic control retarded the thickening of the glomerular basement membrane in adolescent diabetic patients compared with the control group with poorer glucose control. In the same study serum AGE

(advanced glycosylated end products) levels at the start of the study proved to be a significant predictor for the progression of early morphological kidney damage, whereas the mean HbA1c at the start was not (Berg et al. 1997). Rudberg and colleagues (1997) found that in microalbuminuric diabetic adolescents a decreasing glomerular filtration rate was associated with mean HbA1c and basement membrane thickness, and prolonged hyperglycaemia and diabetes duration explained the severity of glomerulopathy. In a 35 years' follow-up study from the Joslin clinic (Krolewski et al. 1996) a strong predictor of the development of end-stage renal disease was the level of glycaemic control during the first two decades of IDDM.

However, the threshold level of hyperglycaemia capable of triggering complications at kidney level has yet to be established. Krolewski (1995) showed that the slope of the relationship between the risk of developing microalbuminuria and HbA1c was almost flat for HbA1c values below 8.1 per cent, while it rose steeply with higher HbA1c values.

Puberty: The kidney experiences significant growth during healthy childhood and adolescent development, reaching mature size by the age of 18. Glomerular size changes proportionately and correlates with body surface area and age (Akaoka et al. 1994). In a study by Lawson and colleagues (1996), nephromegaly was found in pubertal diabetic patients. Kidney size, glomerular filtration rate and filtration fraction were increased compared with healthy controls and were associated with current hyperglycaemia as assessed by HbA1c. There was also a higher frequency of microalbuminuria in postpubertal patients when compared with adult diabetic patients with the same disease duration. This raises the question whether puberty accelerates the nephropathic process, since nephropathy is extremely rare before puberty (Mathiesen et al. 1986).

Smoking is an independent risk factor for microalbuminuria in adolescent and adult diabetic patients (Chase et al. 1991, Couper et al. 1994). The mechanisms by which smoking increases albuminuria are not yet known. Smoking two cigarettes in an hour increases systolic blood pressure and proteinuria during the period of smoking in hypertensive patients with diabetic nephropathy (Sawicki et al. 1996). Albuminuria diminishes significantly once smoking has ceased (Chase et al. 1991).

Hyperlipidemia is associated with significantly higher insulin resistance, total cholesterol, and VLDL-triglycerides and LDL/HDL ratios in microalbuminuric insulin-dependent patients compared with their non-albuminuric controls (Yip et al. 1993).

Diet: Studies indicate that a high protein intake and hyperglycaemia may be involved, independently, in the deterioration of kidney function by increasing the glomerular filtration rate and the work load of the kidney (Reynolds 1987). Toeller and colleagues (The Eurodiab IDDM Complications Study Group 1997) discovered the consumption of animal protein to be significantly greater among macroproteinuric than

among normoalbuminuric diabetic patients. There is evidence from clinical studies that the progression of renal disease is delayed by early protein restriction. Pedrini and associates (1996) investigated via meta-analysis 108 IDDM patients and 1305 non-diabetic patients with a dietary protein restriction ranging from 9 to 36 months and found the restriction to effectively slow the progression of diabetic and non-diabetic renal disease. On the other hand, Kontessis and colleagues (1995) have suggested that the amount of diet protein is not crucial and that greater importance may attach to the quality of the protein. The authors found that vegetable protein might have advantageous effects on the risk of nephropathy.

10.2 Retinopathy

Prevalence

Retinopathy is a common complication of insulin-dependent diabetes. Kokkonen and associates (1994a) evaluated insulin-dependent diabetic patients born between 1963 and 1968 who had been diagnosed before the age of 15. At a mean age of 21.6 years with a diabetes duration of 13.3 years retinopathy was diagnosed in 80 per cent of the patients: 70 per cent had background and 10 per cent proliferative changes. One was blind. Seven years later, 61 of the patients were re-evaluated: all had retinopathy, 29 per cent experiencing proliferative changes. Two patients were blind. The data agree with those of Goldstein and group (1993). Falck and colleagues (1993) found retinopathy in 10.8 per cent of their young pubertal or post-pubertal diabetic patiets with a mean age of 12.2 years in the province of Oulu. In a Swedish study by Kernell and coworkers (1997) the frequency of retinopathy in adolescents aged 14.6 yr with a diabetes duration of 8.0 yr was 14.5%. The frequency is very likely underestimated because of dropouts (28.6%), who were older and with a longer duration of diabetes.

Screening and evaluation of retinopathy

Laser photocoagulation proving effective in preventing blindness from proliferative retinopathy in at least 70 per cent of cases (The Diabetic Retinopathy Study Research Group 1978), there are now recommendations for screening retinopathy (The Finnish Diabetes Association, Retinopathy working party 1992). Fundus photography is recommended in addition to yearly ophthalmoscopy beginning in adolescence.

Risk factors for retinopathy

It is assumed that the aetiology of retinopathy is multifactorial.

Hyperglycaemia, the most important risk factor, causes changes in the sorbitol pathway, non-enzymatic glycation and rheologic mechanisms (Frank 1991). Many studies show a significant relationship between glycaemic control and the rate at which retinopathy develops together with the risk of proliferative retinopathy (Falck et al. 1993, Goldstein et al. 1993, DCCT 1994, Kokkonen et al. 1994). Kawagishi and associates (1995), in their retinal blood flow analysis using duplex Doppler sonography, showed that IDDM patients had haemodynamic alterations without diabetic retinopathy. Hyperglycaemia was a contributing factor in impaired retinal circulation. Danne and coworkers (1994) have shown that a glycohaemoglobin value greater than HbA1c 9.0 per cent is critical for the development of retinopathy in adolescents. The authors found that above that cut-off point retinopathy increases exponentially. The DCCT-study (1994) showed that good glycaemic control has a beneficial effect, which can first be detected after 3 years of therapy, on all levels of retinopathy.

Duration of diabetes: The pre-pubertal duration of diabetes is considered controversial in the development of retinopathy, because some investigators have not detected retinal changes before puberty (Kostraba et al. 1989, Goldstein et al. 1993). However, Goldstein (1993) showed that retinopathy developed significantly sooner in younger-onset than older-onset diabetic patients. The post-pubertal duration in both groups was the same. The conclusion was that the pre-pubertal duration does impose a risk of developing retinopathy. Kokkonen (1994a) and Falck with associates (1993) have agreed with this conclusion.

Puberty seems to accelerate retinopathy, but the affecting factors remain obscure. The insulin resistance in puberty may have an effect through glucose control (Amiel et al. 1986).

Hypertension, especially systolic blood pressure, is an independent and significant risk factor for retinopathy (Teuscher et al. 1988). Diastolic blood pressure has also been found to correlate significantly with retinopathy (Kondonouri et al. 1996). Diabetic adolescents have higher systolic and diastolic blood pressure than their healthy controls (Cruickshanks et al. 1985).

Smoking is associated with an increased prevalence of microvascular complications (Chaturvedi 1995). The effect is mediated at least partly through poor glycaemic control. Young diabetic smokers have poorer glucose control than their non-smoking controls (Kokkonen and Paavilainen 1993).

Of *nephropathy* there is an old legend that an IDDM patient who has nephropathy must also inevitably have retinopathy. Chavers and colleagues (1994) investigated this

possible relationship via renal biopsies and fundus photographs and found that significant microvascular disease of the kidney is more common in patients with advanced retinopathy and hypertension. Ninety-two per cent of patients with advanced retinopathy, moreover, evinced diabetic glomerular changes.

10.3 Neuropathy

Diabetic neuropathy is not a single entity but rather a diverse group of disorders exhibiting a wide range of clinical manifestations. The role of persistent hyperglycaemia in the development of neuropathy is not yet evident. It is assumed that nerve damage begins early in the course of diabetes and subsequently becomes symptomatic.

Peripheral neuropathy

Clinical evidence of diabetic neuropathy may not be manifest during youth, but investigators have found a higher prevalence of sub-clinical neuropathy in young people with insulin-dependent diabetes compared with healthy controls. Already five to six months after the diagnosis of diabetes peroneal nerve conduction velocity has been found to be slowed (Allen et al. 1992). Davis and colleagues (1997) detected sub-clinical neuropathy in 9.1% of diabetic adolescents. Hyllienmark and associates (1995) found in their population-based study that 57 per cent of adolescents with a 7-year duration of diabetes had signs of neuropathy. Long-term poor glycaemic control and increased body length were independent risk factors. In another study by Allen and colleagues (1997) there was some suggestion that chronic hyperglycaemia may be more detrimental to the nerves in male subjects.

In the DCCT study (1992) and subsequently in the Oslo Study (Amthor et al. 1994) intensified insulin treatment with subcutaneous insulin infusion was found to retard the deterioration in nerve conduction velocity observed in diabetic patients

Cerebral dysfunction

The question of irreversible brain damage caused by recurrent hypoglycaemia has recently aroused renewed interest with the rise in hypoglycaemic episodes during intensified insulin treatment in the DCCT study. The DCCT-study (1996a) found no relationship between neuropsychological functioning and recurrent hypoglycaemia.

Autonomic neuropathy

Although symptoms of autonomic nervous dysfunction are rare in young diabetic patients (Veglio et al. 1993), signs of cardiovascular dysfunction are found in 7.3 vs. 0.8 per cent compared to healthy controls (Ziegler et al. 1992). Wawryk and coworkers (1997) found changes in heart rate variability in 15% of adolescents with IDDM. A diminished counter-regulatory response to hypoglycaemia has been found in children and adolescents with new onset IDDM compared to healthy controls (Hoffman et al. 1994).

11 Patient education

11.1 Development of patient education

The need for education in diabetes care would appear self-evident since diabetes is a condition in which success is dependent upon patients' skills and major changes in behaviour making possible the management of the complex regimen of diet, exercise and insulin injections necessary for attaining good glucose control.

The importance of education in diabetes was recognised as early as the beginning of the twentieth century; at the Joslin Clinic the classroom became a cornerstone of diabetes treatment soon after the introduction of insulin in 1922. R.D. Lawrence, one of the first recipients of insulin and the leader of British diabetes care, stressed the need for appropriate knowledge and skills as well as appropriate attitudes if a successful life for diabetics was to be achieved.

Based upon a number of relatively small but impressive clinical studies the causal relationship between glycaemic control and diabetic microangiopathy was accepted by an increasing number of diabetologists; hence the near normalisation of metabolic control to prevent diabetic microangiopathy was formulated as the primary therapeutic goal in type 1 diabetes. A number of diabetologists felt that patient education aiming at self-control and self-treatment should play a key part in reaching this therapeutic objective. Assal, Canivet, Berger and others founded the Diabetes Education Study Group (DESG) of the European Diabetes Association in 1979 in Geneva (Assal et al. 1983). Education, encouragement and training of patients to actively take over increasing parts of their therapy and thus step by step render themselves more independent of physicians and medical institutions became primary objectives of the DESG. In the late 70s and early 80s diabetes patient education emerged as a prime topic of interest in diabetes care.

There are some 93 studies of educational interventions published between 1978 and 1986 (Padgett et al. 1988). From 1986 to September 1999, 142 published studies of educational interventions in diabetes, 51 of them in IDDM, according to Pub Medsearch, can be found.

In the early 70s the Finnish Diabetes Association began establishing summer camps for families with diabetic children. While the main purpose was recreation, education in diabetes self- care was also provided by nurses on hand. By the mid-70s Finland's State Committee for Diabetes gave a recommendation on diabetes care (Valtion sokeritautitoimikunnan mietintö 1976) which included a call for the Finnish Diabetes Association to oversee the implementation of diabetes patient education. In 1980 the Association established an education centre, the Diabeteskeskus, with the mandate to develop and organise patient education. Since then various educational courses have been offered to diabetic patients as medical rehabilitation. Courses for diabetic children and adolescents are organised during the summer vacation season, and courses in patient education have likewise been continuously arranged for heath care personnel.

11.2 Goals of diabetes patient education

Generally, the goal of diabetes education is to teach diabetic patients the basics and objectives of treatment: to provide knowledge, skills and attitude to self-care which give patients the best possible chance to attain well-being and a high quality of life (Koivisto et al. 1995). In the 1980s, insulin and education regimens have both evolved, through intensive therapies using multiple daily injections, into a fully computerised delivery system. Diabetes education, like insulin treatment, is no longer simple. The American Diabetes Association developed national standards for diabetes education (National Standards and American Diabetes Association review criteria for diabetes patient education programs 1986) which were revised in 1995 (Task Force to Revise the National Standards). The standards emphasise individual assessment of educational needs, comprehensive instruction tailored to individual needs, and the importance of follow-up.

Adolescents constitute a distinctive group in diabetes patient education. These young people need to be taught the daily management of diabetes and to be encouraged to take responsibility for their own care. They also need support in coming to terms with a chronic illness and working emotionally, cognitively and behaviourally through the limitations which such an illness imposes. They need to be cognisant of the effects of diabetes on their lives yet not allow the illness to dominate their daily lives (Brown et al. 1991). Because parents are in charge of their diabetic children's care until adolescence, it

may often be difficult for the diabetic adolescent to acquire the independence and autonomy in diabetes self-care.

Although a great many diabetic adolescents do take responsibility for their diabetes there are teens who neglect their self-care when striving to be more like their peers, and who give their parents reason to distrust them. Adolescence in general is moreover characterised by risky behaviour. The amount of alcohol drunk at one time can often be large, and 25–30% of adolescents smoke cigarettes (Rimpelä et al. 1996a). For these young diabetics the conflicts between the natural activities of adolescence and the very different adjustments required by self-care may result in a crisis. Diabetic adolescents may find social relations difficult: an insulin injection before a meal may seem to attract too much attention and thus tends to be neglected. Insulin-resistance in adolescence is an additional factor debilitating metabolic control, which in turn can make a young diabetic deem the whole diabetes treatment unsuccessful.

11.3 Content of diabetes education

To ensure that diabetic patients master their diabetes care, their understanding, motivation and skills must be developed in an educational program. Diabetes education entails instruction in the diagnosis of diabetes and ongoing education thereafter. At the onset it is important to give only the most necessary, "life-saving" instruction: diabetes as a disease, injections of insulin, the basics of diet, blood glucose measuring, and hypoglycaemia. In follow-up education these basic topics are expanded upon and, in addition, elements essential to diabetes care such as the goals and importance of good treatment, acute and late complications, exercise, special situations, illness, travelling, foot care and social matters are dealt with. Psychological aspects, especially recognition of psychological disturbances, depression, eating disorders and psychosomatic symptoms, are emphasised in advanced diabetes education (Koivisto et al. 1995, Task Force to Revise the National Standards 1995). Every member of the health care team is involved in the teaching of diabetes care.

11.4 Educational philosophies

Compliance model

Compliance-centred philosophy is a traditional authoritarian treatment model. Dunn (1988) defines compliance as the extent to which a person's behaviour coincides with medical advice. As such it involves two-way communication between physician and patient with rights and responsibilities on each side. In another context a compliant patient may mean one who thoughtlessly carries out any instruction from any authority, no matter how unpleasant or difficult this might be. Ludvigsson (1980) distinguishes between three different types of compliance: compliance without influencing attitudes, identification and internalisation. Identification involves the adoption of another's behaviour because the relationship with that person is good and is of importance for the understanding of self. For a person to achieve internalisation it is essential that the message fit into his/her existing system of values. Internalised behaviour is very resistant to influence. Until recently, the primary goal of diabetes patient education had been patients' high compliance with a given treatment regimen. Patients who have juvenile diabetes are expected to follow a daily regimen of insulin injections, dietary restrictions, self-monitoring and physical exercise. In criticism of the treatment of diabetes it has been argued that patients are forced to submit to a regimen they neither understand nor are motivated to follow and which sharply contrasts to their former habits and routines (Ludvigsson 1980). Diabetes care, with its demands for regularity, is in conflict with objectives especially belonging to adolescent development. Non-compliance with a given diabetes regimen is common among adolescents.

Studies of compliance among diabetic adolescents

Compliance has been measured by adherence to daily treatment; insulin injections, self-monitoring of blood glucose, diet and exercise.

Kovacs and associates (1992) found in their 9-year follow up that 29.5 per cent of 95 diabetic girls and boys had become non-compliant with medical treatment. The cumulative risk of becoming non-compliant during the first 9 years following diagnosis was 0.45. Years 3 and 4 seemed to be the period of highest risk. Noncompliance typically tended to emerge at the age of 15 and was only increased and protracted with age. Several investigators agree that non-compliance among adolescents increases with age and diabetes duration (Huttunen et al. 1989, Jacobson et al. 1990, Virtanen 1992). As

might be expected, non-compliant patients evince poorer metabolic control than those who adhere to treatment.

For adolescent diabetics who have dealt with their condition for years, social competence, self-esteem and aspects of family function were neither protective nor risk factors, but major psychiatric diseases were associated with non-compliance later in the course of IDDM (Kovacs et al. 1992). Koski (1991) found that stress in the family was a significant factor underlying non-compliance at the diagnosis of diabetes. In a study by Lane and associates (1988) sociability and curiosity in diabetic adolescents were found to be associated with better metabolic control. Sociability and curiosity may reflect greater adaptability or flexibility which improves a school-aged IDDM patient's ability to cope with the difficulties and responsibilities involved in diabetic management.

Non-compliant diabetic adolescents tend to possess a good self-concept and a high level of knowledge about IDDM (Hamburg et al. 1982, Burroughs et al. 1993). These authors suggest that these are young people who may not want to deal with adherence to diabetes care in front of their peers. It may be easier to go along with the crowd and thereby maintain self-esteem despite the price paid in terms of the consequent negative effect on metabolic control. Another explanation is that the acquisition of a great deal of knowledge about diabetes is a coping effort on the part of these adolescents in response to the stress brought on by their poor diabetic control.

Improving compliance with self-care

It might be imagined that the whole problem of neglecting diabetes self care can simply be solved by strengthening compliance.

Galatzer and colleagues (1982) used psychological counselling in family therapy and found that it improved patient compliance. They concluded that with children the initial period after diabetes diagnosis should be considered a period of crisis requiring special multidisciplinary services to reduce psychosocial maladjustments and improve compliance.

Simell and associates (1995) studied the influence of short-term and long-term initial hospital stay on family adjustment at the diagnosis of diabetes. A stay of 1-3 weeks upon the diagnosis has been used for teaching the diabetic patient and his/her family self-care and inducing them to adopt it in daily routine. In a short-term hospital stay the teaching is connected with the problems appearing in self-care at home after initial life-saving instruction. There was no difference in adjustment to diabetes or glucose control between short- and long-term stays.

Rose and colleagues (1983) subjected their young diabetic patients with poor metabolic control to anxiety management training and found that it improved glycaemic control. The reliability of the study is questionable, however, because 30 of the 36 patients involved declined to take part and also because the methods used for assessing glucose control were Diastix-strips and 24-hr quantitative urine glucose measurement. There was no decrease in the subjects' personal assessment of tension and anxiety.

Another method involved using a peer group to improve compliance in young diabetic patients. In a study by Kaplan and colleagues (1985) patients underwent daily social learning exercises designed to improve social skills and ability to resist peer influence. Metabolic control improved and was associated with self-reported compliance. Lorini and coworkers (1990) implemented group education at one-month intervals and found it produced significantly improved diet compliance within 3 months.

Blood glucose self-monitoring is one of the most neglected aspects of treatment. There have been several interventions with the object of enhancing patients' technical skills and compliance with blood sugar monitoring (Belmonte et al. 1988, Lebovitz et al. 1978, Snyder et al. 1992, Wilson et al. 1986, Wysocki et al. 1989).

Poor compliance with exercise regimens in diabetic adolescents was brought out by Huttunen and coworkers (1989). Marrero's group (1988) evaluated a self-motivated home exercise program and found that it increased aerobic fitness measured by maximal oxygen uptake and improved glycaemic control.

In the DCCT study (1993) educational aspects were not emphasised, but there were detailed diabetes instructions during the implementation phase: patients in the intensive group were taken into the department for 1–4 days, where skills related to diabetes self-care were instilled. Dietary information was given to both this group and the control patients. Self monitoring of blood glucose was presumed 4 times per day at the minimum with additional measurements one night per week. This was followed by a minimum of a monthly clinic visit and frequent telephone contacts with the intensively treated cohort by a multidisciplinary team of diabetes nurse educators, dietitians and mental health professionals, all overseen by a physician. All team members were experts in diabetes management and together developed uniform treatment philosophy (DCCT 1995a). For the adolescents the study lasted an average of 7.4 years. The result was patients' significantly improved metabolic control and a decrease in long-term complications. The cost, however, was a rise in the frequency of patients' hypoglycaemic attacks.

Health belief model

Improvement of diabetic patients' adherence to a medical regimen has been a challenging task. One attempt to understand the dynamics underlying compliant and non-compliant behaviour is the development of the Health Belief Model. This theory posits that people will generally not seek health care or comply with medical regimens unless they possess minimal levels of relevant health motivation and knowledge, view themselves as potentially vulnerable and the condition as threatening, are convinced of the efficacy of intervention, and see difficulties in undertaking the recommended action on their own (Becker 1977).

The application of the Health Belief Model to diabetic patients raises certain issues specific to the nature of the disease. Ludvigsson (1980) and later Harris and coworkers (1982) deemed the Health Belief Model to be applicable to diabetes care; for example, patients were expected to be responsible for their daily care, which presumes a tremendous alteration in life style encompassing diet, exercise, medication, blood testing and foot care. Furthermore, the disease is chronic and often leads to serious complications which can be life altering. The Health Belief Model is considered a useful framework for psychological variables which have proved successful predictors of patient compliance. There are several different scales developed for measuring Health Belief Model- relevant beliefs (Becker et al. 1985, Harris et al. 1987).

Locus of control

The psychological construct of locus of control (Rotter 1966) helps to understand the concept of self-management. The locus of control is a concept envisaging the manner in which subjects interpret the causal relationship between their behaviour and the various situations with which they are faced. Individuals who firmly believe in their own ability to cope with anything that might happen to them are regarded as having an *internal* locus of control. On the other hand, individuals who believe that what happens to them is largely dictated by external factors are likely to have an *external* locus of control. Later developments included measures of internal-external expectancies as they related specifically to health and illness (Wallston et al. 1976). The locus of control was reconceptualised by the same authors (Wallston et al. 1978) as the multidimensional health locus of control (MHLC) scale, where internality remained unchanged, but externality was separated into two dimensions: belief in control by others, labelled the "*Powerful Others*" dimension, and belief in fate or chance, labelled the "*Chance*" dimension. In view of a suggestion that measures specific to diabetes may be more strongly associated

with adherence to treatment regimens and metabolic control than are generic measures, there were two attempts to develop multidimensional diabetes locus of control scales (Bradley et al. 1984, Ferraro et al. 1987). Such measurements have been considered appropriate in diabetes because it is a disorder in which there is an ongoing struggle to control the illness and not allow it to control one's life. Various studies designed to investigate the links between locus of control and compliance, and between locus of control and metabolic control, have been carried out in recent years. The relationship between metabolic control and the locus of control has been discovered to be controversial. Brown ans associates (1991) showed that diabetic adolescents with better metabolic control tended to be more internally controlled than those with poor control, whereas in a study of poor diabetic control by Hamburg and Gale (1982) it was found that boys tended to be more external and girls more internal than was the case among those with better control. This sex difference was interpreted as reflecting sex differences in response to stress. The locus of control is amenable to alteration through education (Moffat and Pless 1983). These latter authors found that the locus of control in 156 diabetic adolescents changed towards internal control over the course of a three-week camp. There are now many concepts related to a person having control of his or her situation; personal control, self efficacy, learned resourcefulness.

11.5 Traditional teaching and learning strategies used in diabetes education

1. Lecturing has been employed to educate groups of patients. It is time-saving, economic and easy for the educator. Its disadvantage is the passivity it imposes on the learner, who retains the information only briefly unless it is put to use almost immediately. Frequently there is no opportunity for the lecturer to take into account the learners' individual needs.

2. Individual counselling is the method most frequently used in diabetes patient education. It can be interactive and the patient may express his or her own perceptions. Success depends upon the skills of the counsellor.

3. Group discussion has many advantages, one of the most important being the possibility of sharing personal experiences. This allows the educator to form a wider impression of the patient based upon his /her behavior in the group. The educator must be adept at encouraging silent patients to participate while ensuring that verbal talented patients do not dominate the group. Group discussions have been used in camp program settings, and they are equally popular in different education situations.

4. A popular method for inculcating skills required for diabetes self-care such as insulin injection and blood sugar measuring, is for patients to put into practice what teachers have just demonstrated to them.

5. Audio-visual aids, including food models, slides, posters, film strips and video-tapes, play a very useful role in patient education. Because audio-visual methods place the patient in a passive role, follow-up discussion is important.

6. Role-playing has been popular in diabetes camps, particularly among adolescents, and has the advantage of bringing the participants' attitudes and perceptions to light. To employ such a method successfully, an educator must be skillful and sensitive and possess a high degree of ease in the expression of emotion.

7. Reading can be a very passive, low-retention method of learning or an active and potent one, depending upon the disposition of the learner. Diabetes associations have developed an abundance of educational material.

8. Communication via modeem or telephone between patient and physician, especially to transmit data from SMBG, has been in use over the past few years (Marrero et al. 1995).

11.6 A new education method, Tutorial Problem-Based Learning

Problem-Based Learning (PBL) is a group educational method previously employed in academic teaching but not in structured patient education. There are only two short studies of the PBL method applied to diabetes patient education. The first pilot study involved diet education with a video tape in a camp setting (Pichert et al. 1994a). This was repeated in a later study (Schlundt et al. 1996).

At universities PBL has been in use since the 1960s, when the medical school at Mac Master University, Hamilton, Ontario first introduced this entirely new approach to medical education. The problem-based learning method has since spread to Europe, the Middle and Far East, and Australia. Since the start at Mac Master University approximately 60 medical schools have implemented, at least in part, a problem-based learning approach in their curricula. The PBL has been implemented in theTampere University Medical School since 1991.

Students work from the out set in tutorials, basing their work on "case studies" or "case situations". The "case" presented can be in the form of one or more pictures, a written description, a video, or a personal presentation. The students are trained to discover relevant knowledge based on the situation presented to them. An important feature is early emphasis on communication skills and direct patient contact, as well as

an ongoing pursuit of a deeper theoretical knowledge of basic science throughout the entire program. The method's structure comprises five stages which require students' independent study in addition to group discussion. These five basic elements are: 1. encounter with the problem, 2. free inquiry-questioning, brainstorming and recall of knowledge relevant to the problem as well as identification of what needs to be known to fully understand the problem, 3. identification of learning issues, 4. presentation of knowledge derived from independent investigation of learning issues, 5. problem-solving. The task of the tutor is to ensure that the educational goals, defined for every case, are reached (Walton et al. 1989). The method's advantages are a) the structuring of knowledge for use in a clinical context. Education is most effective when it is undertaken in the context of future tasks. Education driven by the challenge of putting what is learned into practice, and integrating it into the overall reasoning required for evaluating and resolving problems, promotes a structuring of knowledge which is also reinforced through practice. b) the development of an effective clinical reasoning process. c) the development of effective self-directed learning skills. The skills making possible self-assessment and self-directed learning allow the student to become sensitive to personal learning needs and to locate and make effective use of appropriate information resources, as well as d) an increased motivation to learn. The perceived relevance of work with medical problems and the challenge of problem-solving provide a powerful learning incentive (Barrows 1986). Students in PBL have reported greater autonomy, innovation and involvement and have been more sure of themselves in handling uncertainty when compared with students in a conservative curriculum (Bligh 1995). The Problem-Based Learning method as such includes the empowerment philosophy.

Empowerment-philosophy

Together with the liberalisation of diabetes treatment via multiple insulin injections and blood glucose self-monitoring, and along with the simultaneous democratisation of society, the motion of empowerment has steadily gained attention and respect. In 1990 the Education Committee of the University of Michigan Diabetes Research and Training Centre, which developed patient and professional education programs, concluded that the traditional compliance-based approach was an inappropriate conceptual structure for the practice and evaluation of diabetes patient education. The centre adopted a different approach, referred to as patient empowerment (Funnell et al. 1991). The major assumptions underlying the empowerment philosophy are that:

1. human beings have physical, intellectual, emotional, social, and spiritual components in their lives which interact in a holistic and dynamic fashion;

2. to be healthy, human beings must be able to actualise these physical, intellectual, emotional, social and spiritual components of their lives;
3. human beings have the inherent right and responsibility to make the major decisions regarding the conduct of their own lives;

Therefore, in the empowerment view, the primary purpose of diabetes patient education is not to improve compliance through the recommendations of health care professionals, but rather to prepare patients to make informed decisions regarding their self-care. In order to take responsibility for their self-care, patients with diabetes must gain an insight into their own values, needs and goals, as well as specific knowledge about diabetes and its treatment. Diabetes education designed thus to empower patients requires appropriate attitudes, knowledge and skills on the part of diabetes educators. The Michigan Diabetes Research and Training Centre developed, implemented and evaluated a professional education program designed to foster the development of the attitudes and skills needed in empowerment patient education. However, while improved skills and attitudes were found at the end of the 3-day course, the long-term impact of the program is not yet known (Anderson et al. 1991).

In a 6-week empowerment program education course, the self-efficacy and glucose control of diabetic patients improved when compared to controls without such education (Anderson et al. 1995).

11.7 Education interventions in diabetic adolescents

According to Medline there are more than 100 educational interventions in IDDM published between 1970 and 1997. Twenty-eight are concerned with diabetic adolescents (Appendix 1). The various types of intervention may be classified as follows on the basis of their main goal:

1. Patient education (didactic emphasis)
2. Enhanced patient education (behavioural emphasis, employing a combination of techniques)
3. Diet instruction
4. Exercise instruction
5. Self-monitoring instruction
6. Social learning/behaviour modification
7. Relaxation training-biofeedback, yoga, meditation etc.
8. Counselling via peer support, mental health professionals or clinicians

11.8 Evaluation of patient education in diabetic adolescents

A number of problems attend in diabetes education interventions carried out with diabetic adolescents. The educational philosophy and often the education process and methods applied are insufficiently described. Another problem is the small size of the study populations. Refusal to participate is quite common among young patients, as is evident in several studies. The study populations are often highly selected. Voluntary patients are sought in newspaper advertisements or solicited over the telephone. Only the study by Simell and associates (1991) was population-based. The great variation in patients' ages is another confounding aspect. A great many changes occur in adolescents over a short period of time, and thus findings may be widely different depending on the age and developmental stage represented in the study group.

The main outcomes in studies made with diabetic adolescents are data on glucose control, technical skills and various psychological symptoms. Aerobic fitness is measured in exercise interventions, lipids in diet studies, and technical skills in the self-monitoring of blood glucose. The follow-up has been either entirely lacking or was undertaken over only a short time. The long-term effects of interventions have yet to be determined. The longest follow-up was that in the DCCT study, 7.4 years.

AIMS OF THE PRESENT STUDY

The aims of the present study were to investigate

1. The feasibility of the PBL method in patient education adapted to clinical practice and evaluate the method in both practical and economical terms, and
2. to ascertain the effect of the PBL method on diabetes management and glucose control, and the personal, social, psychological and physical health of diabetic adolescents recently transferred from the paediatric department to the clinic of internal medicine

PATIENTS

12 INCLUSION OF PATIENTS

In 1992 an outpatient clinic for diabetic adolescents, "Diabetes youth clinic," was established in the Department of Internal Medicine at Tampere University Hospital. The patients come from the surrounding area, with a population of 440,000 inhabitants. All diabetic adolescents were referred from the paediatric clinic to the diabetes youth clinic once their fast physical growth had settled and they had attained sexual maturity. Between 1992 and 1994, 89 consecutive adolescents were transferred to the department. All were asked to participate in the study, with the exception of two boys (one had just been released from prison and the other was homeless). A third boy was excluded from the study due to moving from the area. All remaining patients and one or both of their parents in 79 (87%) families agreed to participate in the study and gave their written consent. These 86 patients were paired according to sex and age ± 2 yr. and duration of diabetes ± 2 yr. The matched pairs were allotted to two groups; the PBL group and the control group.

The groups of healthy controls were classmates in local vocational and high schools, group I from grade 1 and group II from grade 3. The healthy controls in group 1 and group II were consequently different subjects. Study questionnaires were delivered to all pupils in the classroom, but answering and returning of the papers was voluntary. The volunteers confirmed their participation by signing the questionnaires. Control group I was composed of 189 pupils in the first grade and control group II of 175 in the third grade, 86% and 73% respectively of those to whom the questionnaire was addressed.

13 Demographic data on the patients

The patients were randomised into a PBL and a control group, 43 in each. The mean age was 16.7 (SD 0.6) years in both groups and diabetes duration 8.6 (SD 3.8) years in the PBL and 8.2 (SD 3.9) years in the control group.

Thirty-five per cent of the families in the PBL group and 44% in the control group had members with insulin treated diabetes. In the PBL group 25% of the families and in the control group 22% had a first-degree relative with insulin-treated diabetes (Table1.)

Table 1. Demograchic data and other characteristics of patients and healthy controls

Characteristics	Patients					Healthy controls			
	PBL-group N = 43 n/mean	SD	Control group N = 43 n/mean/	SD	p	Group I N = 189 n/mean/	SD	Group II N = 175 n/mean/	SD
Sex									
Male	26	26				93		65	
Female	17	17				96		110	
Age (years)	16,7	0,6	16,7	0,5	ns	16,2	0,7	18,6	1,2
Duration of diabetes (years)	8,6	3,8	8,2	3,9	ns				
First-degree relative with DM in family	10/39		9/40		ns				

p = The PBL-group vs. control group (diabetic)

At the transfer phase the patients were finishing basic schooling or had already started their vocational school or high school education. In the PBL group 81% were in high school or entering it, 14% in vocational school and 5% at work. In the control group 54% were in or starting high school, 44% vocational school and 2% at work. The PBL and the control group differed significantly (p=0.008) in schooling. During the 2 years the statistical difference remained (Table 2.).

No difference was found between the social class and the education of the parents in the PBL and in the control group.

Table 2. Schooling of patients and healthy controls

School	Patients			Healthy controls	
	PBL group %	Control group %	p	Group I %	Group II %
At transfer					
high school	81	54		82	
vocational school	14	44		17	
left school	5	2			
			0,008		
At the end					
high school	78	49			65
vocational school	15	37			34
left school	7	14			
			0,020		

p = The PBL- vs. control group (diabetic)

STUDY DESIGN

The study was a prospective population-based controlled randomised study.

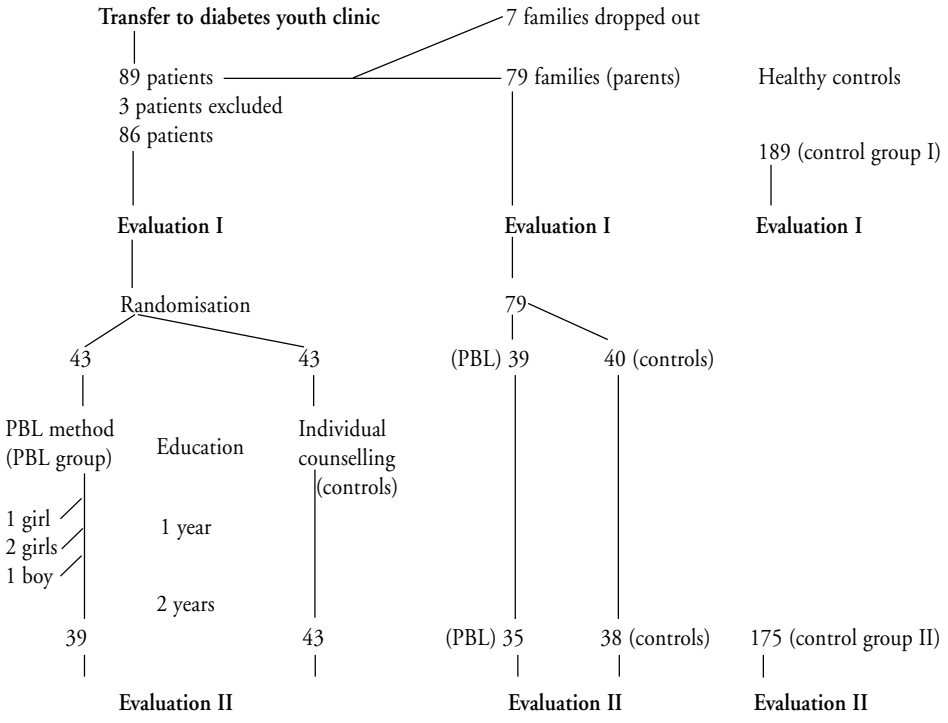

Figure 2. Study design

The first evaluation was made during the first visit to the diabetes clinic at the Department of Internal Medicine, when all patients received questionnaires to fill in. The items comprised demographic data, diabetes treatment, attitudes, depression, quality of life and personality.
The second evaluation took place during the 11th visit after an education period of 2 years including 10 clinic visits. The patients filled in the same questionnaires as at the transfer phase and in addition the locus of control scale.

The tests for autonomic neuropathy and eye fundi photography were made likewise at the transfer phase and at the end. Serum lipids, lipoprotein(a) and two specimens of urine microalbumin were checked yearly, as well as the clinical status. HbA1c was examined at every clinic visit with 10 weeks intervals.

Patients and controls were admitted to the ward only for urgent reasons such as ketoacidosis or other severe condition.

The questionnaire for parents was filled by one or both of the parents at transfer and at the end of the study. There was one questionnaire per family.

Group I (healthy controls) filled in the questionnaires at the beginning of the study and group II (healthy controls) at the end. The questionnaires for healthy controls comprised a personality inventory and a depression and quality of life inquiry.

The study was approved by the ethical committee of Tampere University Hospital.

14 EDUCATION

14.1 PBL method in practice

General goals

The goals of the PBL group education were to provide the diabetic patients with the necessary knowledge and skills required for everyday diabetes self-care, and to tender them responsible and motivated to treat themselves and to attain good metabolic control and thereby good physical and psychological health and social competence.

Group sessions for the PBL group

Instruction took place in group sessions held during each clinic visit. The groups of four to seven patients remained constant throughout the 2-year education period. There

were eight groups in all. Every session was scheduled according to the teaching program. The issue to be learned was presented in the form of a case of diabetes. The cases depicted were of young diabetics with whom the patients could identify themselves. The group gathered around a table and discussed the case, trying to solve the problems it posed. Group members were asked to tell if they had experiences like the problem in question. For matters unclear to patients educational materials were on hand. Different solutions were proposed to everyday problems with diabetes. The nurse and the physician tutored the group and ensured that the educational goals of the session were attained. According to the PBL method the role of the physician and the nurse entailed mainly steering, not teaching. It was intended that the atmosphere of the education sessions was relaxed and informal in order to induce participants to speak freely. An afternoon snack or light lunch, depending on the time of day, was served during the session. Each session lasted 60–90 minutes. During the interval between the education sessions the patients were expected to adapt the new knowledge to their own diabetes practice.

The physician (the author) was the same throughout the study, but there were two stand-ins for the nurse, who was temporarily engaged in other duties. The author was trained in the PBL method in connection with the reform in teaching method at Tampere University, but the nurses became familiar with the technique by participating in the group sessions.

Learning topics

(The cases and the detailed goals of education sessions are presented in Appendix 2.)

1. Insulin
2. Diet
3. Diet, special situations
4. Blood glucose self-monitoring and the goals of glucose control
5. Exercise
6. Checks during ambulatory visits, long-term complications
7. Hypoglycaemia
8. Sick days
9. Social security
10. Motivation

14.2 Individual counselling for the control group

A conservative individual counselling method was used covering the same scheduled topics as in the PBL group, but no cases were presented. Teaching took place with the aid of education booklets. In each outpatient clinic visit about 60 minutes was devoted to consultation and education. The physician spoke first on a general level about the issue to be learned and the nurse followed up with more detailed instruction.

The goals of education in the individual counselling group were the same as in the PBL group.

METHODS

15 QUESTIONNAIRES

Every patient answered the questionnaires*:*

Demographic data and patients' self-care practice and attitudes towards diabetes (Appendix 3). There were questions on insulin injections, home tests, consumption of alcohol, smoking, participation of parents, personal goals and control in treatment, and visions of the future.

Diabetes-related knowledge (Appendix 4) was tested by a multiple-choice questionnaire at the phase of transfer from the paediatric clinic, and a problem-solving format at the end of the study (Appendix 5).

Questionnaires 3–5 were constructed by the author.

Personality inventory (Appendix 6) "Personality traits" was used to measure a patient's personality. This inventory has been validated by Markku Ojanen of the Department of Psychology, University of Tampere. The inventory included 21 personality traits described on a continuous scale 0 to 100. Patients were required to choose the most suitable example for their situation. These scales are based on a visual analogue similar to the VAS scales.

Depression inventory (Appendix 7), the short form by Beck and Beck (1972). The Beck depression questionnaire consisted of 13 questions, which had four alternatives in each and every question yielded a score ranging from 0–4. The sums of the scores 0–52 were graded as depression: 0-4 none or minimal, 5–7 mild, 8–15 moderate and 16+ severe.

Quality of life (Appendix 8) was assessed by a modified questionnaire DQOL, designed for adolescents in the DCCT study (Siebert 1991). The DQOL can be regarded as a battery of related sub-tests. Each sub-test or scale assesses quality of life from a different vantage point. It has four primary scales: general satisfaction, satisfaction with diabetes care, diabetes-related worry , and social-related worry.

Satisfaction: questions 1–17A, of which questions 8–17A were common to healthy controls and may be considered a measure of general satisfaction. Questions 1–7A measured satisfaction with diabetes care.

Impact of diabetes: questions 1-24B social-related worry:, questions 1–12C diabetes-related worry.

Quality of life with diabetes (DQOL): the mean of the sum of the scores of satisfaction, diabetes-related and social worry.

Global health perception: one item in the test, 18A, where the patient was asked to compare his/her health with peers, was also suitable for healthy controls.

Responses to questions range from 1 (very satisfied) to 5 (very dissatisfied). Social and diabetes-related worry scales were ranked from 1 (no impact, no worry) to 5 (constant impact, always worried). The results yielded a mean of fixed questions.

The questionnaire DQOL was validated by the DCCT (1988).

Locus of control (Appendix 9): diabetes-related concepts concerning the mastering of the disease were surveyed via a questionnaire developed from the "Diabetes locus of control" scale (Ferraro et al. 1987, Aalto and Kangas 1993). The test inquiry consists of 27 statements, which are grouped into four items; internal, external (health care personnel), fate, and others (close people). The subject was asked to choose the most suitable alternative of five; 1 agree completely to 5 disagree completely (Likert's scale). The scores given to each of the four items were summed and the means calculated and statistically analysed.

Diet diary, which the patients were asked to fill in for 3 days; one weekend day and two week-days. The diaries were gathered at the transfer phase and at the end of the study. Instruction in keeping the diet diary was given by the diabetes nurse at the same time when the patients received the forms to fill in.

Parents answered the following questionnaires:

Demographic data and attitudes of parents, (Appendix 10) a questionnaire which asked parents' background and their estimation of the adjustment to diabetes in the family and their attitude to and participation in diabetes self-care. Both parents together, or one of them filled in the questionnaire. Social classification into four grades and education into three grades was based on that used in sociological studies in Finland (Valkonen 1985). Statistical significance was calculated for fathers and mothers separately.

Healthy controls answered the following questionnaires:

Demographic data (Appendix 11)

Personality inventory (Appendix 6)

Depression test (Appendix 7)
Quality of life test (Appendix 12), modified from the test used in the DCCT.

16 Insulin injections

The reported number and doses of daily insulin injections were recorded at every clinic visit.

Patients were administering both short- and intermediate-acting insulin in single injections as well as premixed combinations. Short-acting insulin was injected three times before main meals, or before breakfast and dinner if a 50/50 combination of short- and intermediate-acting insulin was injected before lunch. A premixed 10/90 combination of short- and intermediate-acting or pure intermediate insulin was injected during an evening snack before going to bed. Patients were encouraged to change their insulin doses according to the results of self- monitoring of blood glucose.

17 Diet

In diet education low fat foods were recommended and estimation of carbohydrate portions for insulin dosage emphasised. Patients in both the PBL and control groups kept a diet diary for 3 days at the transfer phase and at the end of the study. The diaries were checked via patient interviews conducted by the nurse or the physician using when needed the help of different measures and pictures of food. An experienced nutrition therapist calculated diet diaries according to the Nutrica-data program (Health Insurance Institution, Helsinki, Finland). In the DCCT study, the method of meal-based diet history complemented by an interview was validated and found reliable. The results demonstrated long-term reproducibility of a meal-based diet history, correlation coefficients varying from 0.51 to 0.72 (Schmidt 1994).

18 Exercise

Frequency of exercise per week, at least half an hour at a time, was asked via the questionnaire at the transfer phase and at the end of the study.

19 Self-monitoring of blood glucose

The self-monitoring of blood glucose was checked by examining the patient diaries. The average number of home tests performed by the patient per month was recorded at every clinic visit. If the patient had not brought the diary, the number of home tests was estimated as 0.

20 Glycosylated haemoglobin HbA1c

During ambulatory visits to the Diabetes youth outpatient clinic at 10-week intervals, a venous blood sample in non-fasting state was taken. Glycosylated haemoglobin HbA1c values were measured by the FPLC method with Mono S (Pharmacia Biotech, Sweden). Reference values were 4.0–6.4 per cent.

21 Hypoglycaemia

Hypoglycaemic events were checked during every clinic visit by asking the patients about symptoms of severe hypoglycaemia.

Severe hypoglycaemia was defined as a state of unconsciousness or a state where the assistance of another person was needed. Patients were asked to analyse all episodes of severe hypoglycaemia- whether they occurred while waking or sleeping, were there any warning symptoms, were there any possible contributing factors such as exercise, alcohol, omission to eat, etc.

22 Smoking

Patients were asked about their daily intake of cigarettes at the transfer and at the end of the study.

23 Alcohol use

Individual alcohol use was recorded using the questionnaire at the transfer and at the end of the study.

24 Lipids

A non-fasting blood sample was taken in the laboratory of Tampere University Hospital. Total cholesterol and triglycerides were measured by the enzymatic colorimetric method, and HDL-cholesterol by the enzymatic colorimetric method after Dextran sulfate/MgCl precipitation (Johnson and Johnson Clinical Diagnostics, Rochester, NY, USA). Lipoprotein(a) was measured by solid-phase two-site immunoradiometric assay (Mercodia, Uppsala, Sweden).

25 Blood pressure

Blood pressure was measured during each clinic visit, a total of 11 times during the study. Measurements took place with the patient in sitting position after 10 minutes' rest; blood pressure was measured twice with a sphygmomanometer on the right arm; the lower pressure was recorded.

26 Weight and height

Weight was measured during each clinic visit with an electronic scale. Height was measured with a stadiometer at the transfer phase of the study, during the fifth clinic visit, and at the end of the study.

27 Microalbuminuria

Urine microalbuminuria was measured by nephelometry (N antiserum to human albumin, Behring OSAL 15) from two consecutive timed overnight urine collections taken at the transfer phase, at the fifth outpatient visit and at the end of the study. Microalbuminuria was defined as albumin excretion ≥ 20 γg/min. Albumin excretion under the measurable value <1.7 γg/min was recorded as 1 γg/min. The mean of two consecutive collections was used in statistical analyses.

28 RETINOPATHY

A retinal examination was performed at the transfer phase and at the end of the study by eye fundus photography with pupils dilated, using a Canon CF-60z camera. The two photographs were wide-angle shots of 60 degrees using colour prints, which were graded blindly by an ophthalmologist, Professor Lotta Salminen, M.D. The amounts of microaneurysms/haemorrhage dots and exudates were counted. Retinopathy was categorised according to the Early Treatment Diabetic Retinopathy Study adaptation of the modified Airlie House classification of diabetic retinopathy (Bonney et al. 1995).
Retinopathy levels for each eye were classified as follows:

level 10: No retinopathy

level 21: Microaneurysms only or haemorrhages only

level 31: Microaneurysms and one or more of the following: definite haemorrhages, hard exudates or venous loops; questionable soft exudates, intraretinal microvascular abnormalities, or venous beading

level 41: Microaneurysms and one or more of the following: definite soft exudates or intraretinal microvascular abnormalities

29 AUTONOMIC NEUROPATHY

At the transfer phase and at the end of the study a battery of tests were applied under standard conditions at the clinical physiology laboratory in Tampere University Hospital.

Valsalva maneuver

Patients were subjected to a constant pressure of 5–6 kPa, by blowing into a mercury sphygmomanometer with a small artificial leak to ensure an open larynx for 15 seconds. The reactions were followed for 40 seconds and the Valsalva and tachycardia ratio were calculated from the ratio between the longest RR interval after release of pressure, and the shortest RR interval during sustained pressure.. The procedure was repeated three times and the mean calculated.

Deep breathing test

The normally occurring sinus arrhythmia was exaggerated by intentional deep breathing to maximal vital capacity in a rhythmical manner. The inspiration and expiration phases both lasted about 5 seconds. Recordings were made three times, each lasting 60 seconds, with the subject supine. The mean was calculated and recorded as deep breathing difference and deep breathing index, i.e., the ratio between the longest RR interval during expiration and the shortest RR interval during inspiration.

Isometric hand grip test

During this test the subject pressed the dynamometer with 30 per cent of his/her maximum strength. This was continued for at least 3 minutes and for as long as 5 minutes. Blood pressure and heart rate were monitored by ECG.

Orthostatic test

Here the subject rested for 15 minutes supine before rising quickly. Heart rate and blood pressure were then immediately measured with the patient in erect posture, and thereafter every minute for 7 minutes.

Diagnostic classification

Normal values for cardiovascular tests were those extrapolated from the normal values published by Piha (1988). Pathologic values were those $\leq 50\%$ of normal value and borderline between $> 50 \leq 80\%$ of normal value (Piha 1989).

STATISTICAL METHODS

Results are expressed as mean ± SD if not otherwise stated. Student's t-test (2-tailed) was used to compare the PBL and the control group at the transfer phase and at the end. Non-parametric tests, Mann-Whitney and χ^2 -test, were used in analyses of data from questionnaires including Likert's scale. Repeated analysis of variance, or paired T-test were used to evaluate the change between different time points. Pearson's correlation coefficient was used in searching for correlation between variables. A logistic regression analysis was used to study associations between dichotomous dependent variable and independent variables. Analyses were done using SPSS-statistical software.

RESULTS

30 FEASIBILITY OF THE PBL METHOD IN DIABETES PATIENT EDUCATION

30.1 The PBL learning method in practice

By arranging group learning sessions in connection with routine clinic visits the PBL method was shown to be applicable in the patient education program. The cases simulating diabetic adolescents' everyday life were suitable for discussions in the learning sessions. Mastering of diet, injection of insulin and blood sugar measurements were clinical skills which demanded continuous training during the education period. Group sessions afforded a suitable situation for this.

Attendance at education sessions

Four of the patients discontinued the visits. One of them omitted most of the controls, two moved away and the fourth became pregnant and was followed up at the maternity clinic. There were to be 430 individual clinic visits in both the PBL and the control group during the education period of 2.0 years. In the PBL group there were 31 sporadic cases of absence from the sessions, usually owing to examinations at school. The missed sessions were compensated with an individual clinic visit with counselling. In the control group there were only 6 neglected visits. However, the number of absences in the control group cannot be compared with that in the PBL group, because the patients in the control group could change their date of visit if necessary.

Although most of the patients in the PBL group were obliged to give more time to the education sessions compared with the control group, dissatisfaction with the time used was not different between the groups. At the end of the study 20% of the patients in the PBL group and 31% in the control group were dissatisfied with the time spent on the clinic visits.

Group work

Depending on the group and the subject, the discussions could be very lively, but sometimes the participants were reluctant to speak. In some groups one or two participants dominated and it was the tutor's task to induce the members to work democratically. In some groups all participants seemed to be shy and initiating discussion was laborious. Discussions seemed to be easier when the nurse, who was closer to the patients, worked as the tutor. Generally the topics of the sessions appeared to be interesting and easy to identify.

Suitability of the case examples in the PBL program

1 Insulin

The first subject, insulin, was an interesting theme and provoked discussion. The case involved a young diabetic subject who had lost his/her insulin on an inter-rail journey, described as the case. In several groups a typical solution to the problem was to imagine that there was a doctor with insulin in his bag near by. Another was to go to a hospital. It was generally unknown that insulin could be freely bought from any pharmacy.

2–3 Diet

In the diet session everyone in the group was to analyse his/her own diet recall .The diet session was not the best possible, because many of the patients knew their diet schedule from memory and wrote it as a model of their diet history. Dieting was practised by means of a snack or lunch served during the session. Alcohol was a difficult topic at group sessions, because there were always one or several participants who boasted of consuming great amounts of alcohol at a time. The attitude towards smoking was generally negative in the group, and during the study several patients made attempts to stop smoking.

4 Home tests

Working out different problems concerning SMBG seemed to be motivating. Several of the students in the groups planned to increase their blood sugar measurements after this education session.

5 Exercise

In the exercise session the participants learned how to adjust insulin injections according to their exercise or how to change their insulin dosage when going to bed late or going to sleep in the morning. There appeared to be a number of new things to learn.

6 Hypoglycaemia

The hypoglycaemia case was somewhat confusing. A young diabetic boy who suddenly collapses in the morning was described. The participants did not always know what the question was about. Finally the case proved to be inspiring for a many-sided discussion. Use of alcohol was also discussed in this session.

7 Exceptional situations and sick days

A diabetic student with a common cold was described in the case presented. Most of the members of the groups had insufficient knowledge of diabetes treatment during sickness. Only a few used a strip for testing ketone bodies during sick days. The goal of the session was to help participants to understand the basic principles of diabetes treatment during sickness. Many had difficulties in understanding the metabolism of hyperglycaemia and ketone bodies.

8 Long-term complications

This case describing a young diabetic man with incipient long-term complications, failed to provoke lively discussion. In general, it seems that discussion of long-term complications may be felt as ominous and difficult.

9 Social security

A visit of a social worker to the group was useful in that the patients were in the stage of planning their studies and profession.

10 How to sustain motivation

This session was directed towards the future. There were discussions of different means of preventing subjects with depression or other adversities from neglecting daily diabetes care. The discussions were inspired by a case of a young diabetic man rejected by his girl friend.

30.2 Economy of the PBL method

The time spent on education was calculated according to the time schedule. The time reserved for one small group was on the average 70 minutes plus 15 minutes per patient for an individual meeting with the physician. This amounted to 2 times (physician and nurse) 8 groups x 10 times x 70 minutes + 430 x 15 minutes = 17.650 minutes = 294 hours for education and care of the patients in the PBL group during the two years. In the control group there was a time of 30 min reserved for meeting the physician and the nurse each. Totally this makes 430 x 60 minutes = 430 hours for the control group. The PBL method consumed 68% of the time needed in the control group. In practice, the diabetes care and education in the PBL group meant a 5.4 weeks' contribution of the physician and 2.3 weeks of the nurse. In the control group the corresponding inputs were 5.8 and 5.4 weeks respectively. In Finnish marks the saving in the PBL group was about 20.000. If the group sessions were conducted by the nurse or the physician by turns, the saving would have been 93 hours (31%) more in the PBL method. In this way the PBL-method would have consumed 47% of the time spent in the control group.

31 Effect of education, comparison of methods

31.1 Diabetes-related knowledge questionnaires

The questionnaire at the transfer phase was multiple choice-type, whereas that administered at the end was problem-solving. There was a significant correlation, $r = 0.43$, ($p = 0.009$) between the total scores of the tests in the control group but not in the PBL group.

The total scores from the diabetes-related knowledge questionnaire did not differ between the groups, but there was a difference in answering the question concerning prevention of hypoglycaemia between the PBL and the control group at the transfer phase. The scores were 1.3 and 1.8 (max 3) ($p = 0.024$) respectively. At the end of the study the PBL group had higher scores on the insulin question than the control group, 2.1 vs 1.5 (max 3) ($p = 0.036$). One reason for the better scores might be the more comprehensive handling of the topic of insulin in the PBL groups compared to individual counselling. There was no difference on the other questions between the PBL group and the controls. HbA1c and scores of the knowledge tests did not correlate in Pearson's correlation test.

31.2 Management of diabetes self-care

Insulin

Insulin injections

All patients in the PBL group changed their two or three injections to four daily injections. Only one boy in the control group continued with three daily injections (Table 3).

Table 3. Number of injections/day

Number	PBL group	Controls
	%	%
At transfer		
2	2	2
3	5	7
4	93	91
At the end		
3	0	2
4	100	98

Omitting insulin injection

At the transfer phase 37% of the patients in the PBL group and 28% in the control group reported that sometimes they forgot an insulin injection. At the end of the study the corresponding figures were 42% and 39%. There was only one boy in the control group who reported that he often forgot insulin injections.

Insulin dose

The insulin dose u/kg increased significantly both in the PBL ($p = 0.011$) and in the control group ($p = 0.037$), but there was no difference between the groups by repeated analysis of variance (Table 4). There was no difference in insulin dose/weight between girls and boys at transfer or at the end of the study. The short acting/intermediate insulin dose ratio in the PBL group was 1.28 (SD 0.41) at the transfer phase and 1.21 (SD 0.33) at the end. In the control group the ratio remained the same 1.32 (SD 0.43).

Table 4. Insulin dose u/kg weight

	PBL group		Controls		
	mean	SD	mean	SD	p
	u/kg		u/kg		
At transfer	0,95	0,18	0,91	0,17	ns
At the end	1,01	0,21	0,99	0,15	ns
p of change	0,011		0,037		

Diet

Compliance in keeping diet diary

The compliance in the three days' diary-keeping was incomplete. Eight patients, four in each group, were excluded due to missing and indistinct data. In addition, 19 patients at the transfer phase, and 11 at the end, failed to keep a diary. There was no significant difference between the HbA1c of those whose diet diaries were missing or rejected compared with those whose diaries were accepted by the nutrition therapist. The data in the diet diaries were analysed separately in both genders because of the different phases of physical development; the girls had mainly ended their growth while the boys were still growing. The correlation of total energy, amount of carbohydrates, fat and protein between the first and the second diet histories was highly significant, r ranging from fat 0.47 to fibre 0.65 ($p < 0.001$).

Daily intake of nutrients and fibre

The energy content recorded in the diet diaries of the boys remained the same throughout, 2,381 (SD 429) to 2,411 (SD 599) kcal in the PBL group and 2,462 (SD 428) to 2,294 (SD 440) kcal in the control group. The figures of girls were 1,742 (SD 350) to 1,681 (SD 354) kcal and 1,814 (SD 315) to 1,676 (SD 318) kcal respectively.

No difference was found in the energy contents of the diet or in the daily intake of nutrients between the PBL and the control group at the transfer phase or at the end. (Table 5).

Table 5. Percentage of total energy of different nutrients, and fibre content (g/day) in diet

Boys	At transfer					At the end				
	PBL group (N=17)		Controls (N=24)			PBL group (N=18)		Controls (N=17)		
	Mean	SD	Mean	SD	p	Mean	SD	Mean	SD	p
Carbo-hydrates	46,6	4,2	46,1	4,0	ns	46,1	7,1	46,7	5,6	ns
Fat	35,8	4,8	35,5	4,3	ns	34,0	8,3	35,1	5,4	ns
Protein	17,3	2,7	18,0	2,2	ns	17,5	2,8	18,1	2,2	ns
Fibre g/day	36	11	35	9	ns	29	9	33	12	ns
Girls	(N=14)		(N=14)			(N=13)		(N=15)		
Carbo-hydrates	46,4	4,7	45,5	4,5	ns	49,3	6,7	44,7	7,8	ns
Fat	35,8	5,1	36,2	6,3	ns	33,6	7,9	36,5	8,0	ns
Protein	17,6	2,5	18,3	2,3	ns	16,9	2,3	18,5	2,1	ns
Fibre g/day	24	7	23	7	ns	21	6	20	5	ns

No correlation was found between the proportions of different nutrients and HbA1c at any phase of the study in either group.

Mean daily carbohydrate content

The mean daily carbohydrate intake among girls was 202 g and among boys 272 g. Girls took 40% of daily carbohydrates as snacks and 60% in main meals. Among boys the share of snacks was 56%. There was no difference between the PBL and the control group in the carbohydrate content of corresponding meals. The share of carbohydrates remained the same during the study.

Exercise

There was no significant difference in reported exercise frequency between the PBL and the control group at the transfer phase or at the end, nor was there any difference in changes in exercise frequency during the study by χ^2-test (Table 6). HbA1c was similar in both groups in those who reported exercising at least every other day, compared with

those who exercised less frequently. No difference was found in the frequency of exercising between those attending high school or vocational school by χ^2-test.

Table 6. Reported frequency of exercise

	PBL-group		Controls	
	At transfer N = 42	At the end N = 39	At transfer N = 43	At the end N = 43
	%	%	%	%
Exercise every day	26	13	32	32
Every other day	33	31	33	26
1–2 times per week	38	44	26	33
No exercise	3	12	9	9

Self-monitoring of blood glucose

At the transfer phase 65% of the patients in the PBL group and 86% of the patients in the control group practised self-monitoring of blood glucose. The frequency of the tests varied from six to 90 measurements per month. During the study the number of those who used SMBG increased to 77% in the PBL-group and decreased to 81% in the control group. Clinically there was an occasional suspicion of cheating in home tests.

Those who reported using SMBG significantly increased the frequency of tests ($p < 0.001$) from 18 to 29 measures/month in the PBL group and from 20 to 30 measures/month in the control group. The groups did not differ from each other by repeated analysis of variance. The frequency of SMBG was similar in both genders. At the transfer phase there was no difference in HbA1c between those who measured blood glucose compared to those without SMBG. However, at the 11th clinic visit the HbA1c of those who used SMBG ≥10 test/month (n=28) in the PBL group was 9.0% (SD 1.2) vs. 10.7% (SD 2.0) in those who did not use it at all (n=8) ($p = 0.006$). The values in the control group were 8.9% (SD 1.1) (n=32) vs 10.4% (SD 1.2) (n=8) respectively ($p = 0.002$).

31.3 Independence in self-treatment

Injection of insulin, meal portioning, estimation of results of home tests and changing of insulin dose were the areas where the parents participated most frequently in daily treatment. At the transfer phase one fifth of the parents injected insulin daily, at the end

only two. Progress towards independence was achieved in all aspects of self-care. No statistical difference was to be found between the PBL and the control group in parents' participation in daily diabetes care.

31.4 Glucose control

Glycohaemoglobin HbA1c

At the end of the study, after 2.2 years from the transfer phase, there were 39 patients in the PBL group and 43 in the control group. According to analysis of variance for repeated measures HbA1c improved significantly ($p < 0.001$) without difference between the groups (Figure 3). At the transfer phase HbA1c in the PBL group was 10.3% (SD 1.8) vs.10.3% (SD 1.5) in the control group and at the end HbA1c values were 9.3% (SD 1.5) and 9.2% (SD 1.2), respectively. No significant difference was found by t-test between the groups at any clinic visit.

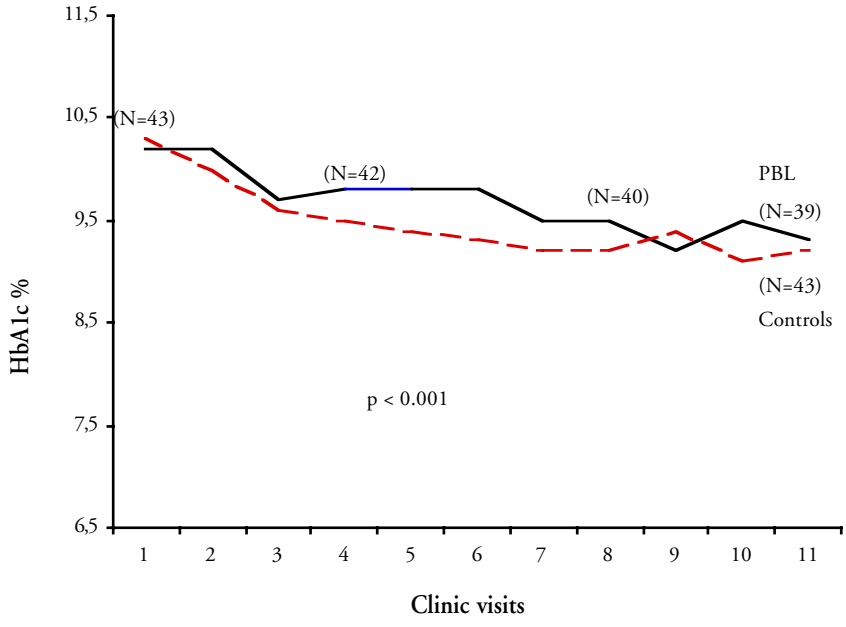

Figure 3. Development of HbA1c in the PBL and control groups during the study

The girls in the PBL group had a significantly higher HbA1c level at every clinic visit compared with those in the control group (Figure 4). HbA1c values in the girls decreased in the PBL group from 11.3% (SD 2.0) to 9.8% (SD 2.1) vs. 10.4% (SD 1.6) to 9.0% (SD 1.2) in the control group. The corresponding HbA1c values for boys were 9.6% (SD 1.2) and 9.1% (SD 1.1) in the PBL group and in the control group 10.2% (1.5) and 9.3% (SD 1.3).

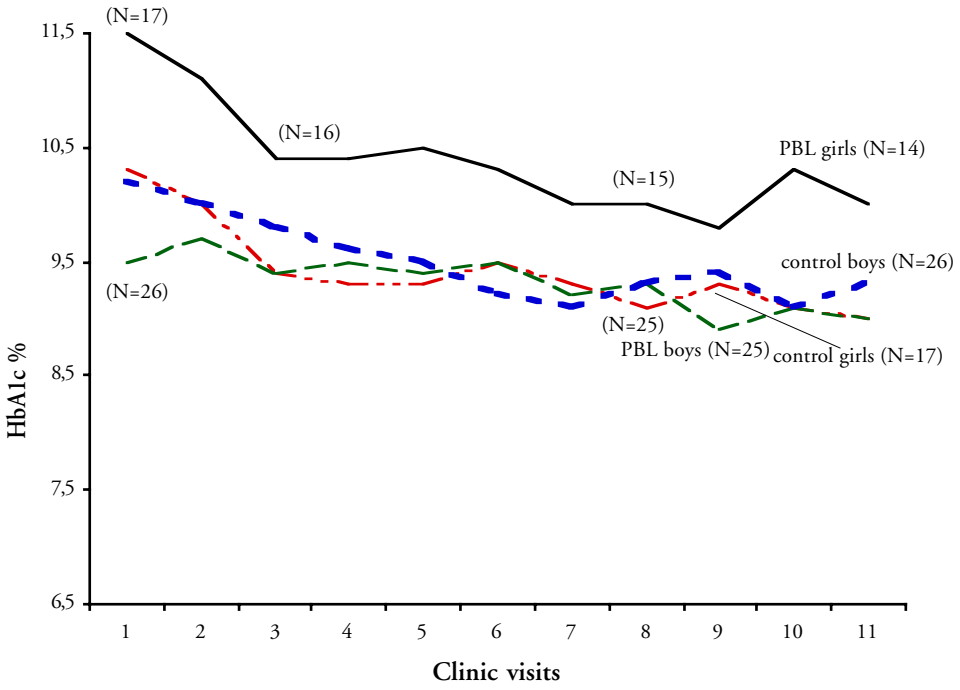

Figure 4. Development of HbA1c among girls and boys in the PBL and control groups

HbA1c in girls with an eating disorder was significantly different from values for other girls (Figure 5). Four of the five girls with an eating disorder were randomised into the PBL group and the remaining one into the control group.

If the girls with an eating disorder were excluded, HbA1c was found to be identical in both genders in the PBL and in the control group.

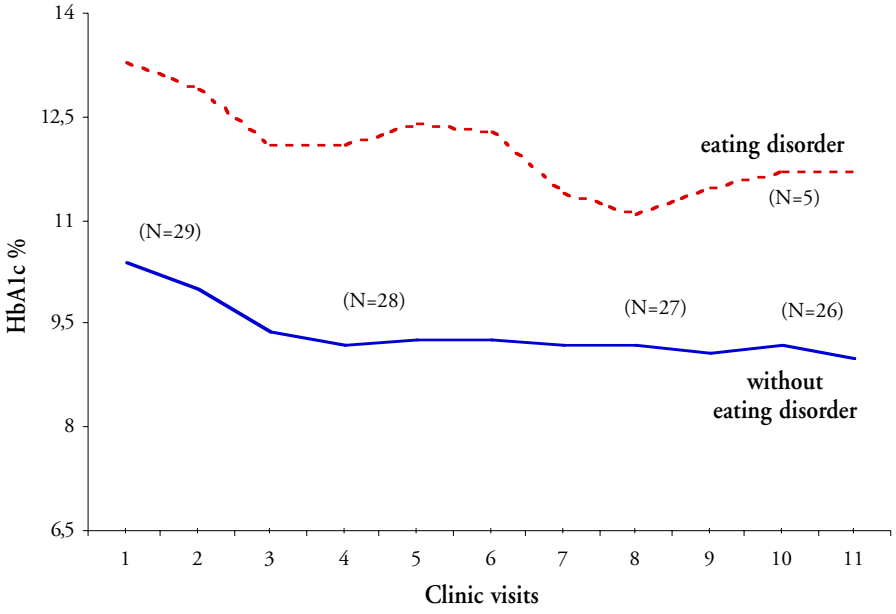

Figure 5. Development of HbA1c during the study in girls with and without an eating disorder

When particular variables were divided into two groups according to HbA1c level ≤ 9% or > 9%, it appeared that the risk factors for arteriosclerosis were higher in poorer glucose control. However, severe hypoglycaemia was more frequent in those with HbA1c ≤ 9% (Table 7).

Table 7. Particular characteristics divided into two groups by HbA1c

Mean of HbA1c	≤ 9 % (N=33)		> 9 % (N=53)		
	Mean	SD	Mean	SD	p
Diastolic RR	70,7	4,5	72,9	4,9	0,027
Cholesterol	4,1	0,7	4,7	0,9	0,002
Triglycerides	1,0	0,3	1,7	0,8	0,000
Insulin dose/ kg weight	0,9	0,1	1,0	0,1	0,000
	N		N		
Severe hypoglycaemia	29		6		0,003
Smokers at the end	9		14		ns

When the patients were divided into three categories by their HbA1c : < 8, 8–9.0 and > 9%, it was found that the number with poor glucose control, HbA1c > 9%, decreased by about 30% in both groups during the study and correspondingly the share of those with better control increased. The changes were similar in both of the education groups (Figure 6).

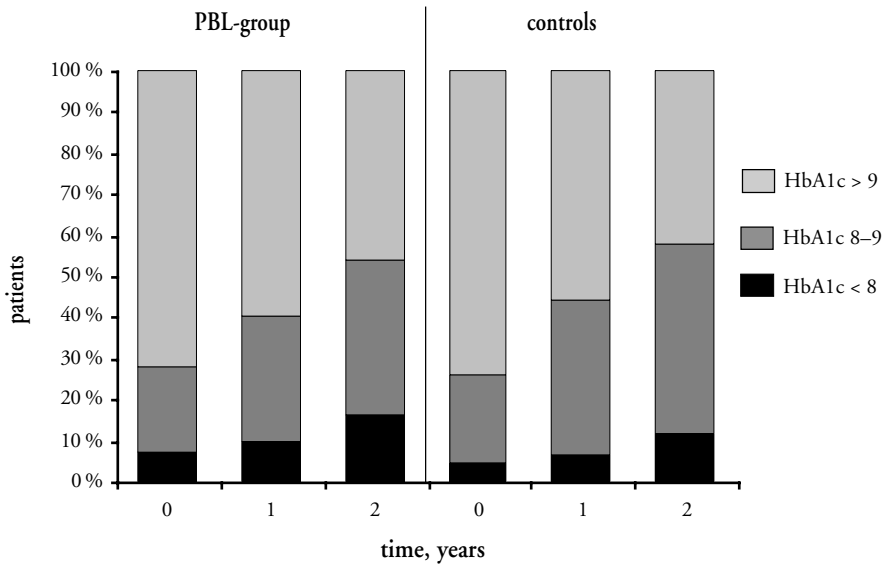

Figure 6. Development of three different glycaemic categories divided by glycohaemoglobin HbA1c value

When the patients were divided into two categories by HbA1c at the first clinic visit, HbA1c > 9% (n=62) and ≤ 9% (n=24), and the groups followed during the study, it was found that patients whose glycohaemoglobin was > 9%, improved their glucose control significantly, ($p < 0.001$). Their HbA1c decreased in the PBL group from 11.0% (SD 1.6) to 9.6% (SD 1.6) and in the control group from 10.9% (SD 1.3) to 9.5% (SD 1.2). In those with better control at transfer the changes were not significant. In the group HbA1c ≤ 9%, the change was from 8.3% (SD 0.5) to 8.7% (SD 1.3) in the PBL group and from 8.4% (SD 0.7) to 8.1% (SD 0.7) in the controls. The changes were similar in PBL and control groups (Figure 7).

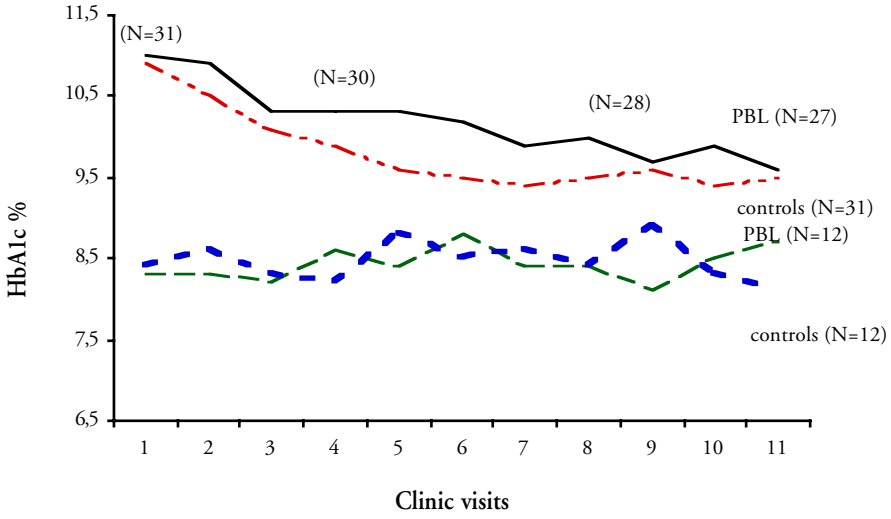

Figure 7. *Development of HbA1c during the study in those with poor, (HbA1c > 9 %), and in those with satisfactory glucose control, (HbA1c ≤ 9 %) at the transfer phase*

Severe hypoglycaemia

Frequency and reasons

Seven patients in the PBL and likewise in the control group, 16.3% of all patients, had events of severe hypoglycaemia. There were 35 events altogether, 15 in the PBL group and 20 in the control group. This constitutes 20.8 events per 100 patient years. Of those

who had severe hypoglycaemia, 57% in the PBL group and 71% in the control group reported more than one event.

There was one girl in the PBL group who reported five events and who had a compulsive need to inject insulin at a definite time, even though no food was at hand. Two girls in the control group with five hypoglycaemia episodes each had a disturbed fear of high blood sugar and injected excessive doses of insulin without measuring blood glucose.

In the PBL group the frequency of severe hypoglycaemia was similar in both genders; among girls 18% and among boys 15%. In the control group, however, severe hypoglycaemia was more frequent among girls, 35% reported one or more severe events vs 4% of boys, ($p = 0.006$) by χ^2-test.

Twenty-nine episodes of hypoglycaemia were nocturnal, 6 occurred in the day-time. There had been a celebration the previous night in eight of the cases, and in at least six of them alcohol was consumed. A treatable source of hypoglycaemia was found in 25 (71%) of the cases. A typical situation was that an adolescent had been out in the evening and stayed awake long and possibly used alcohol, and in the morning after the insulin injection and breakfast had gone to sleep, and the parents had found him or her later in a hypoglycaemic coma.

Four of the nine patients reporting more than one episode of severe hypoglycaemia suffered these events within a short period of 2–4 weeks.

Self-monitoring of blood glucose was similar in patients with severe hypoglycaemia compared to those without.

There was no significant difference in the quality of life, personality or depression between those with severe hypoglycaemia and those without in either group. Several of the severe hypoglycaemia episodes occurred before the topic "avoidance of hypoglycaemia" which was taken up as the 6th in the education program. Nevertheless, hypoglycaemia was already briefly discussed in connection with insulin treatment and home tests, as well as with exercise.

Characteristics in diabetes treatment associated with severe hypoglycaemia

The mean of HbA1c during the study among those with severe hypoglycaemia was lower than that of the patients without ($p = 0.006$), but the HbA1c decrease from the transfer phase to the end of the study was similar between patients with hypoglycaemia and those without. The insulin dose/kg body weight decreased during the study among patients with severe hypoglycaemia compared with an increase among those without ($p = 0.001$), (Table 8). Clinically, in many cases of severe hypoglycaemia the insulin dose was too high in relation to the situation. In most it seemed difficult for the patient

to reduce insulin dose despite advice to do so. Of the variables mean HbA1c, change of insulin dose/body weight, and mean insulin dose (u/kg body weight), only the change of insulin dose/kg body weight emerged in logistic regression test as inversely predictive of severe hypoglycaemia (p = 0.025).

Table 8. Factors associated with severe hypoglycaemia during the study

Severe hypoglycaemia	Yes (N=14)		No (N=68)		
	n/mean	SD	n/mean	SD	p
Sex (number of patients)					0,046
male	5		47		
female	9		25		
Mean HbA1c (%)	8,8	0,2	9,8	0,1	0,006
Mean insulin dose U/kg body weight	0,84	0,04	1,03	0,02	0,000
Ratio of short/intermediate acting insulin	1,3	0,3	1,2	0,3	ns
Change in mean insulin dose u/kg body weight during the study	-0,07	0,13	0,09	0,17	0,001
Mean systolic blood pressure mm/Hg	113,0	9,5	119,9	8,6	0,008

31.5 Hospitalisation

Four patients (9%) in the PBL group were hospitalised once, two of them for acute ketoacidosis, one for poor glucose control and one for a non-diabetic reason. In the control group there were 17 hospitalisations among nine patients (23%). The reasons were ketoacidosis in nine cases, a hypoglycaemic coma in one, poor glucose control in two and other non-diabetic reasons in five patients. One of the boys in the control group was hospitalised 8 times during the study. He had symptoms of depression and had neglected insulin injections, and was repeatedly driven to ketoacidosis and brought to the hospital by his mother. He refused psychiatric consultation.

31.6 Attitudes and responsibility in daily care

Perceived health (Question 18A, Appendix 8)

The patients in the PBL and control groups, as well as the healthy controls, were asked to assess their health compared with peers. At baseline no difference was found between the PBL and the control group, nor between the PBL or control group and the healthy controls. At the end of the study, however, the patients in the control group perceived their health as poorer than those of the PBL group ($p = 0.005$) and also as poorer than the healthy peers ($p = 0.001$) by Mann-Whitney test (Table 9).

Table 9. Perceived health of patients compared to healthy peers (% of subjects)

	Patients				Healthy controls	
	At transfer		At the end		At transfer	At the end
Perceived health	PBL group (N=43) %	Controls (N=39) %	PBL group (N=43) %	Controls (N=43) %	(N=189) %	(N=175) %
Excellent	16	18	18	12	23	18
Good	61	69	56	41	61	64
Satisfactory	23	10	26	45	15	17
Poor	0	3	0	2	1	1
Very poor	0	0	0	0	0	0

When the development of perceptions of health during the study was analysed by dividing the patients into three groups; those whose estimation remained unchanged, improved or worsened, the PBL and the control group differed significantly ($p = 0.040$) (χ^2-test). The members of the PBL group improved their assessment when compared with the control group, where it worsened (Table 10).

Table 10. Changes in perceived health during the study (% of patients)

Perceived health	PBL group N=39 %	Control group N=42 %	p
Unchanged	62	52	
Improved	23	9	
Worsened	15	39	
			0,040

Locus of control (Appendix 9)

The PBL and the control group differed only on the item of external locus; in the control group the external locus was stronger than in the PBL group (p = 0.038) by Mann-Whitney test. Boys and girls did not differ from each other on any item. The external locus correlated with HbA1c at the end, (p = 0.021), but the correlation was not significant in either the PBL or in the control group separately (Table 11).

Table 11. Locus of control estimated on Likert's scale 1–5*

The four items	PBL group (N=37)		Control group (N=37)		
	Mean	SD	Mean	SD	p
Internal locus	1,6	0,3	1,5	0,4	ns
External	3,3	0,5	3,1	0,6	0,038
The others	3,7	0,7	3,5	0,9	ns
Fate	4,3	0,3	4,2	0,5	ns

* Likert's scale: 1= agree totally
2= agree somewhat
3= do not know
4= do not agree
5= totally disagree

Assessment of impact of self-care on diabetes course on a scale 0–10 (Question 23, Appendix3)

At the transfer phase the patients in the PBL and the control groups rated the impact of self-care on their diabetes as 8.1 (SD 1.4) and 8.2 (SD 1.4), respectively, and 8.3 (SD 1.1) and 8.4 (SD 1.2) at the end, (scale 0–10). The increase was not statistically significant. The assessment of the parents in the PBL group was 8.5 (SD 0.9) and in the control-group 8.0 (SD 1.2) ($p = 0.031$) at the transfer phase, and 7.5 (SD 2.3) and 7.7 (SD 1.2), respectively, at the end. The decrease in parents' scores was significant in the PBL group ($p = 0.018$), but not in the control group by paired t-test.

In the PBL group no correlation was found in test results between adolescents and their parents. However, in the control group at the end of the study, the test results between adolescents and parents correlated by Pearson's correlation, $r = 0.413$ ($p = 0.010$).

The HbA1c did not differ significantly whether the adolescents' or their parents' assessment of impact on diabetes increased or decreased during the study.

What will be the impact of diabetes on health in the future (Question 24, Appendix 3)

Most of the diabetic adolescents estimated that diabetes would not change their health in the future, and a quarter thought that their health would improve. Only a minority of the patients believed that their health would deteriorate. Three quarters of the parents anticipated their children's health would be unchanged in the future, only a few believed it would improve and less than a third to worsen. (Table 12).

There was no statistical difference in assessments of the impact of diabetes on future health between the PBL and the control group or between the parents at the beginning or at the end (χ^2-test). HbA1c did not differ in those who estimated that their health would improve when compared to those who thought it would remain unchanged or worsen.

Table 12. Assessed impact of diabetes on health in the future (% of patients and parents)

	Patients			
Health	At transfer		At the end	
in the future	PBL group (N=43) %	Controls (N=43) %	PBL group (N=39) %	Controls (N=43) %
Unchanged	84	71	70	55
Improved	14	26	25	28
Worsened	2	3	5	17
	Parents			
	(N=39)	(N=40)	(N=35)	(N= 38)
Unchanged	64	67	63	66
Improved	15	5	17	5
Worsened	21	28	20	29

Which is the most important goal in diabetes care (Question 22, Appendix 3)

The patients and the parents were given seven different alternatives to grade as goals in diabetes care. At the beginning and also at the end both the PBL and the control group selected as the most important goals "To live like peers" and "Good glucose balance". "To avoid long-term complications" and "Feel fine" were also selected as important. The remaining three alternatives, "To avoid hospitalisation", "Regular daily program" and "To be in good fitness" were seen to be less important. The HbA1c did not differ between those who selected living like peers or good sugar balance or any other of the alternatives as the most important. Both groups of parents estimated the same alternatives as the most important.

31.7 Social function

Personality (Appendix 6)

Personality scales (Detailed results are shown in Appendix 13)

At the beginning of the study the PBL group differed from the control group in lower scores estimating openness ($p = 0.035$) and impulsiveness ($p = 0.028$), but not at the end. No changes were to be found during the study in the scores on any trait, except in the question of feeling anxious. Anxiety increased significantly in the control group from scores of 31.8 to 38.3 ($p = 0.046$), vs. 31.7 to 34.0 ($p = 0.428$) in the PBL group by paired t-test. The scores on the question of anxiety correlated with those on Beck's depression inventory at the transfer phase, $r = 0.325$ ($p = 0.003$) and at the end, $r = 0.595$ ($p < 0.001$).

At the end of the study, those in the control group who had HbA1c < 8% had significantly higher scores in the following traits: activity ($p < 0.001$), dominant ($p = 0.022$) and selfish ($p = 0.003$) than those with HbA1c ≥ 8% by t-test, but not in the PBL group. Otherwise there was no difference between HbA1c categories in the various traits of the personality test.

At the beginning of the study the diabetic adolescents in the PBL group had higher scores in the sense of responsibility ($p = 0.019$), lower in the need of variety ($p = 0.016$), in impulsiveness ($p = 0.003$) and in flexibility ($P=0.033$) than the healthy controls by t-test. At the end the only differences were lower scores on openness ($p = 0.013$), self-confidence ($p = 0.030$) and impulsiveness ($p = 0.022$) when compared to the healthy controls. In the control group the diabetic adolescents had lower scores in self-control ($p = 0.011$) than their healthy peers at the transfer phase. These differences had disappeared by the end of the study. Among the healthy controls higher scores were recorded in self-confidence ($p = 0.014$) and responsibility ($p = 0.005$) in the group of older adolescents (Group II), qualities which may be assumed to be enhanced with age during adolescence.

Smoking

The PBL and the control groups differed statistically significantly in the number of smokers, 14% vs. 28% respectively, ($p = 0.042$) at the transfer phase, but not at the end of the study, 20% vs. 30%. In the PBL group those attending vocational school smoked

more frequently than those in high school, 17% vs. 9% (p = 0.001) at transfer, but not at the end of the study; in the control group those at vocational school were more frequent smokers than patients in high school 53% vs.17% (p = 0.022) at the end, while no difference was found at transfer. The mean number of cigarettes smoked per day at the transfer phase in the PBL group was 9.6 (SD 6.1) and in the control group 9.0 (SD 6.2). At the end the corresponding figures were 8.7 (SD 3.8) and 11.8 (SD 5.8).

The PBL and the control group differed significantly in changes in smoking frequency during the study by χ^2-test (p = 0.035) (Table 13). The number of smokers increased in the PBL group by five boys and one girl, and in the control group by two boys. One boy and one girl in the PBL group (3 smokers dropped out), and nine boys and three girls in the control group continued smoking. One girl both in the PBL and in the control group stopped smoking.

Table 13. Changes in smoking habits at the end of the study (% of patients)

	PBL group (N=39)	Controls (N=43)	
	%	%	p
No smoking	79	65	
Continues smoking	5	28	
Started smoking	14	5	
Stopped smoking	2	2	
			0,035

No difference was found between smokers and non-smokers in frequency of exercise, albumin excretion or HbA1c, but smokers had fewer SMBG per month than non-smokers, at the outset 9.0 (SD 9.9) vs. 21.9 (SD 21.4) (p = 0.008) and also at the end, 16.4 (SD 18.0) vs. 35.8 (SD 35.3) (p = 0.003).

The number of microalbuminuric patients (cu-alb ≥ 20 γg/min) did not differ among smokers and non-smokers.

Alcohol

The frequency of alcohol use was similar in the PBL and the control group at the beginning and at the end of the study. During the study the frequency increased, in PBL from

51 to 87% (p = 0.018) and in control from 53 to 79% (p = 0.004). There was no difference in change between the PBL and the control group (χ^2-test).

At the transfer phase 53% of the girls in the PBL group and 24% in the control group used alcohol at least once a month, at the end of the study 72% and 65%, respectively. Of the boys 19% in the PBL group and 27% in the control group used alcohol at the outset, and at the end 68% and 66%, respectively. There was no difference in the number of alcohol users or the frequency of use between those in high school and vocational school by χ^2-test. The quality of alcohol consumed was stronger in the control group when compared to the PBL group at the end of the study (p = 0.021) (χ^2-test).

31.8 Psychological health

Quality of life (Appendix 8)

The PBL and control groups did not differ at the transfer phase or at the end of the study in total scores on the four tests, DQOL, which may be regarded as a measure of quality of life in diabetes. In the sub-tests scores measuring diabetes-related worry at transfer were significantly higher, 1.9 (SD 0.4) vs. 1.6 (SD 0.8) (p = 0.025) in the control group. The reason for the difference was not evident. There was the difference in schooling between PBL and control group, but no significant difference was found in diabetes-related worry scale scores between those attending high school or those in vocational school. The difference had disappeared by the end. The scores on different tests did not change significantly in either of the education groups, but those on the diabetes-related worry scale decreased significantly when both education groups were tested in combination. General satisfaction was similar between the healthy controls and the diabetic education groups at the transfer phase and at the end of the study.

Depression (Appendix 7)

During the study several patients evinced depression and adjustment problems with diabetes, but only two, one boy in the PBL group and one girl in the control group agreed to ambulatory psychiatric counselling. One girl in the control group suffered severe depression with a suicide attempt with insulin. After the incident, she underwent treatment in the psychiatric department for several months. Her diabetes education and treatment in our outpatient clinic continued during this period.

According to the Beck depression scale the severity of depression at the transfer phase was different in diabetic groups; mean scores were 1.3 (SD 2.1) in the PBL group vs. 3.0 (SD 3.8) in the control group, (p = 0.017). At the end the difference had disappeared, scores were 1.7 (SD 2.8) vs. 2.3 (SD 4.7) respectively. At transfer also the frequency and degree of depression were different in diabetic groups, (p = 0.020), but not at the end. There was no difference in frequency and degree of depression between diabetic groups and the healthy controls by χ^2-test (Table 14). The frequency and degree of depression were not different according to schooling or gender in any of the groups. Depression did not correlate with microalbuminuria or retinopathy in any phase of the study. In diabetic groups there was no statistically significant change in depression scores during the study. Correlation between scores on Beck depression scale and HbA1c was not found at transfer or at the end of the study.

Table 14. Degree of depression according to Beck's inventory (% of subjects)

	Patients				Healthy controls	
	At transfer		At the end		At transfer	At the end
	PBL	Controls	PBL	Controls	Group I	Group II
Degree of depression*	N=43 %	N=43 %	N=39 %	N=43 %	N=189 %	N=134 %
None or minimal	93	75	86	84	76	83
Mild	5	17	8	9	15	8
Moderate	2	8	5	2	9	8
Severe	0	0	1	5	0	1

* scale of scores: 0–4 none or minimal, 5–7 mild, 8–15 moderate and 16+ severe

Eating disorder

There were five girls with an eating disorder matching the criteria of bulimia nervosa, (DSM-III-R), except that the patients did not vomit, but regulated their weight with insulin. The diagnostic criterion for bulimia nervosa is binge eating (rapid consumption of a large amount of food in a discrete period of time), at least twice a week for ≥ 3 months, feeling of lack of control over eating behaviour during the eating binges, and persistent overconcern with body shape and weight, together with vomiting, use of laxatives or vigorous exercise (Rodin and Daneman 1992). Four of the girls with an eating disorder were in the PBL group and one in the control group.

There was a tendency to poorer glucose control, higher BMI and insulin dose/ body weight, more atherogenic lipid values, and more anxiety among the girls with an eating disorder compared with those without. The diet diaries did not reveal the disorder.

31.9 Physical health

Height and weight

Because of the difference in growth between boys and girls during adolescence the data were analysed by gender. Of the girls 61% and of the boys 86% grew during the study. Height and weight increased statistically significantly in both genders during the study, without any difference between the PBL and the control group (Table 15).

Table 15. Development of height, weight and BMI during the study

	Girls (N=31)				Boys (N=52)			
	At transfer		At the end		At transfer		At the end	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Height cm	162,7	5,7	163,2	6,0	176,6	6,5	179,3	6,6
Weight kg	61,1	7,1	63,7	7,5	66,8	10,0	72,6	8,7
BMI kg/cm^2	23,0	2,2	23,8	2,7	21,3	2,5	22,5	2,2

Development of BMI

It was clinically significant that during the study adolescents who did not grow increased their weight, the girls 0.9 kg/m^2 (SD 1.2) ($p = 0.020$) and the boys 1.8 kg/m^2 (SD 0.4) ($p < 0.001$), compared to those who grew, whose BMI increment was insignificant.

According to diet diaries energy intake among the boys who did not grow vs. those who grew was roughly 2,800 vs. 2,400 kcal at the transfer phase and 2,700 vs. 2,300 kcal at the end. Energy intake among the girls was 1,650 vs. 1,850 kcal at the transfer phase and 1,600 vs. 1,700 kcal at the end, respectively.

Frequency of overweight

Overweight was similar in the PBL and the control group during the study. At the transfer phase 5 (12%) of the patients in the PBL and 6 (14%) in the control group had BMI ≥ 25 kg/m^2, 4% of these BMI ≥ 27 kg/m^2. During the study overweight increased; at the end there were 16 (20%) patients with BMI ≥ 25 kg/m^2, nearly half of whom had BMI ≥ 27 kg/m^2. The 5 girls with an eating disorder had BMI 24.4 kg/m^2 at the transfer phase and 25.6 kg/m^2 at the end.

Lipids

Since measurements here were of non-fasting lipid values, LDL-cholesterol was not calculated. It has been found that the cholesterol values in non-fasting and fasting state do not differ (Virtanen et al. 1993). Lipid values in girls and boys are presented separately in view of adolescent development, during which lipid values diverge between the genders (Table 16). There was no difference in lipid values between the PBL and the control group. Use of alcohol, reported exercise frequency or smoking did not correlate with lipid values in either group, nor in girls the use of contraceptive pills.

Nor was any correlation found between lipid values and carbohydrates, protein, fat or P/S ratio in diet.

Table 16. Development of serum lipids during the study

	Girls					Boys				
	At transfer		At the end			At transfer		At the end		
	Mean	SD	Mean	SD	P	Mean	SD	Mean	SD	P
	mmol/l		mmol/l			mmol/l		mmol/l		
Cholesterol	4,95	1,01	4,75	1,33	ns	4,27	0,73	4,14	0,78	ns
HDL-chol	1,38	0,26	1,37	0,26	ns	1,34	0,29	1,23	0,32	0,002
Triglycerides	1,49	0,79	1,68	1,07	ns	1,26	0,64	1,40	0,85	ns

Long-term complications

Nephropathy

The objective was to obtain two consecutive urine collections yearly for three years. However, compliance with urine collections was not complete. One girl who later abandoned the study gave no urine samples; the other 85 made three to six collections during

the 2 years. At the transfer phase 8 (9%) patients gave no samples, and 23 (27%) of the patients gave only one. After the first year, 4 (5%) had given no collections, 19 (22%) one, and in the third year 4 (5%) none, and 14 (17%) one. The mean of the two yearly collections, or the only collection available, was used in statistical analysis. As there was no difference between the PBL and the control group in the number of those with microalbuminuria or in the amount of albumin excretion during the study, data are presented for both of the groups together (Table 17).

Table 17. Albumin excretion during the study (γg/min)

Albuminuria ≥20 γg/min	Yes			No		
	N	Mean	SD	N	Mean	SD
		γg/min			γg/min	
At transfer	10	31,7	13,4	68	7,0	4,9
After 1 year	10	37,0	9,0	71	6,0	4,3
At the end	9	46,5	20,8	69	6,0	4,1

To further evaluate albuminuria, the patients were classified according to their albumin excretion into three categories. Microalbuminuria was considered persistent in those who had microalbumin ≥ 20 γg/min in all three or in the last two consecutive yearly controls, or had microalbumin ≥ 20 γg/min in both urine collections in the third year. Intermittent microalbuminuria comprised cases of albumin excretion ≥ 20 γg/min transiently in yearly controls. Normoalbuminuria was defined as normal albumin excretion in all urine collections during the study. Of all patients 75% had normoalbuminuria, 14% intermittent microalbuminuria, and 10% persistent microalbuminuria (Table 18). Two without microalbuminuria had an ACE inhibitor in use.

Table 18. Albumin excretion (γg/min) in patients with normoalbuminuria, intermittent microalbuminuria and persistent microalbuminuria at the end of the study

Normoalbuminuria			Intermittent microalbuminuria			Persistent microalbuminuria		
N	Mean yg/min	SD yg/min	N	Mean yg/min	SD	N	Mean yg/min	SD
59	5,3	3,6	11	15,9	17,6	8	42,5	23,0

When known factors relating to microalbuminuria were analaysed, it was found that the group of patients with persistent microalbuminuria differed from the normoalbuminuric patients in the amount (p = 0.041) and in energy proportion (p = 0.011) of protein in the diet, in systolic blood pressure (p = 0.002) and in a positive history of hypertension among first degree relatives (p = 0.016). The group of intermittently microalbuminuric patients differed from the normoalbuminuric in a higher protein proportion of total energy in their diet (p = 0.004) and to higher HbA1c (Table 19). During the study all three groups reduced their HbA1c by 1% unit, a change which was significant only in those with normoalbuminuria (p < 0.001).

Table 19. Different variables at the transfer phase in microalbuminuric and normoalbuminuric patients

	Persistent albuminuria (N = 8)			Normoalbuminuria (N = 59)		Intermittent albuminuria (N = 11)		
	Mean	SD	p*	Mean	SD	Mean	SD	p**
HbA1c	10,5	1,9	ns	10,0	1,5	11,1	2,0	0,052
Systolic " "	135,7	15,4	0,002	120,0	12,2	122,7	13,8	ns
Energy proportion of protein in diet (%)	19,5	3,3	0,012	17,3	2,0	19,8	2,9	0,004
Protein in diet g	106,3	13,5	0,044	91,7	19,3	94,9	41,9	ns
Hypertension in first-degree relatives (%)	66,7		0,016	18,8		41,7		ns

p* Normoalbuminuric vs. persistently microalbuminuric patients
p** Normoalbuminuric vs. intermittently microalbuminuric patients

In the PBL group smoking among normoalbuminuric patients increased statistically significantly (p = 0.026), but not among those with intermittent or persistent microalbuminuria. In the PBL group microalbuminuric patients' systolic blood pressure (p = 0.002) and protein content of the diet decreased (p = 0.018) during the study, changes that were not found in the control group.

Retinopathy

Eye fundi were examined at the transfer phase and at the end. At transfer 71 of the patients had their eye fundi photographed. Instead of photography 12 patients underwent ophthalmoscopy carried out by an ophthalmologist. Three of the patients neglected to attend the fundus examination. The result of ophthalmoscopy was normal in all but one, who was found to have a microaneurysm.

At the end of the study 79 of the 82 patients had fundus photography, two neglected to attend for examination, and in one case photography failed and was replaced by ophthalmoscopy.

At the transfer phase 19 (22%) of the patients had signs of retinopathy in one or both eyes defined as microaneurysms, haemorrhages and exudates in the eye fundus. Two years later 25 (30%) evinced signs of retinopathy. The change in frequency was significant ($p = 0.045$). At the transfer phase the level of retinopathy was mild in all but one of the cases; at the end six of the patients (25%) with retinopathy had moderate or advanced non-proliferative retinopathy. None had proliferative retinopathy. Those with retinopathy had a longer duration of diabetes, 10.1 vs. 8.0 years ($p = 0.032$) and more microalbumin in the urine 15.4 vs. 9.0 γg/min ($p = 0.030$). HbA1c was similar in those with retinopathy and those without and no gender difference was found between the groups.

The PBL and control groups did not differ in the frequency or severity of retinopathy at transfer phase or at the end (χ^2-test).

Autonomic neuropathy

There was a significant correlation between the test results at the transfer phase and at the end in the valsalva manoeuvre, $r = 0.53$, deep breathing test, $r = 0.46$, handgrip test, $r = 0.42$ ($p < 0.001$) and acceleration index, $r = 0.28$ ($p = 0.015$).

Two of the patients yielded four pathological results in various tests at the transfer phase, findings which had disappeared by the end. Several patients had single random borderline values.

There was no significant change in the results of the valsalva manoeuvre, deep breathing test, SDs of RR intervals at rest or of the handgrip test during the study. However, the acceleration index and both systolic and diastolic blood pressure upon standing up (30 s) and after six minutes standing (passive orthostatic test) changed significantly during the study. There was no correlation between the change in any of the tests and HbA1c, duration of diabetes, blood pressure or lipids.

When the results of the various tests used in the study were classified as remaining the same, improving and worsening, there was no difference between the PBL and control groups.

DISCUSSION

32 PATIENTS

The patients transferring from paediatric to medical clinic were chosen for the study population to fit the narrow age bracket and for their closely similar situations in life; they were just completing basic school and setting out on secondary education. Moreover, these patients needed education in their diabetes-self care at the stage of detachment from their parents. Adolescence is a phase of life when one's objectives of development are intensely experienced and interest in a chronic disease may be minimal. At this point adolescents with a chronic disease are at risk of developing a crisis with the consequence of rejecting the disease. The population base of the study offered a significant advantage; the diabetes care of the adolescents in this area with 440,000 inhabitants was centralised in the Tampere University Hospital. According to the paediatric diabetologist all diabetic adolescents from the area matching inclusion criteria were included in the study. Of the study population 40% were girls, which is somewhat lower than the prevalence of girls in adolescent diabetic population (48%) (Kela1999). Randomisation resulted in two groups comparable to each other on other measures but schooling; in the PBL group 81% of the subjects were at high school, while in the control group the corresponding proportion was 54%, the others receiving vocational training. Theoretically the difference might influence these adolescents' learning; while a vocational program emphasises a hands-on approach and acquisition of skills, the emphasis of high school education tends to be on intellectual growth. In the knowledge test at the transfer phase those attending vocational school had significantly lower scores compared to those in high school, but at the end the difference had disappeared. Neither was there any difference in daily diabetes care or HbA1c between those attending high school or vocational school. Healthy students in vocational school differ from their peers in high school in their social behavior, including smoking and alcohol use (Rimpelä et al. 1996b), which was also seen in the current study. Four of the patients (9.3%) in the PBL group

dropped out of the study, which is acceptable considering the poor participation of teen-aged patients in many studies (Rose 1983, Tercyak et al. 1998). The drop-outs did not differ in HbA1c from the others at the transfer phase. Of parents 92% at the transfer phase and 89% at the end participated in the study. There was no difference between the PBL group and the controls in parent participation.

33 Methods

The questionnaires concerning the participation of the family as well as the assessment of the goals of treatment were difficult for the adolescents to understand and may have yielded defective answers, thus possibly representing the views of only the most resourceful of the patients. Reports on self-management of diabetes are easily fabricated and reports of injections, home tests and exercise should be taken critically. The validated quality of life scale used in the DCCT study (DCCT 1988) was modified to correspond to Finnish conditions and seemed to work well.

The method used in this study of keeping diet diaries for 3 days with a complementary interview by a diabetes expert seemed reliable compared with the method of diet recall of the preceding 48 hours used by Virtanen (1992) and Pietiläinen and colleagues (1995). The report of adolescents' alcohol intake raises the suspicion that the latter method predisposes adolescents to cheating.

Personality inventory interested the adolescents and seemed easy to fill in. The tests at the outset and at the end of the study correlated significantly by paired t-test in different personality traits, excluding that of the flexibility.

Diabetes-related knowledge was measured by a multiple choice test at the transfer phase; at the end a problem solving format was used. Solving of problems is application of knowledge in practice and as such represents a goal in diabetes education. Thus the problem-solving test is a measure of absorbance of diabetes-related knowledge. Theoretically the PBL method may provide a better readiness to problem-solving than the conservative method, but in both approaches the goal was the same, mastery of diabetes self-care, and thence the use of a problem-solving test as measure of adoption of knowledge is justifiable.

34 EDUCATION METHODS

34.1 The PBL method

Principles

Problem-Based Learning is a constructive group learning method which encourages learners to co-operate in framing problems, gathering resources and expanding their knowledge through discussion, teaching their peers, evaluating information and answering questions. A learner integrates information from his own viewpoint and understanding while being influenced by the group. Research has demonstrated that this method generally promotes motivation to learn, self-esteem and a variety of cognitive abilities, including recall, retention and problem-solving (Albanese and Mitchell 1993). As a result of their parents' participation in their daily care, diabetic adolescents often have a deficient knowledge and experience of their disease. At this developmental phase and while still under parental care, adolescents are open to the influence of their peers (MacKenzie 1990). Group study of diabetes has been used in camps, especially during adolescence, and has proved useful (Schlundt et al. 1996). Because the self-treatment of diabetes demands knowledge and skills it affords a suitable ground for applying the PBL method. The PBL method also becomes a logical tool in implementing the empowerment philosophy, which emphasises the patient's own active role and responsibility in his own care (European Diabetes Policy Group 1998).

34.2 Individual counselling

Individual counselling is the primary method used in diabetic patient education at routine clinic visits and has therefore become a logical control method for this study. The method is teacher-oriented and easily emphasises the teacher's authority while the patient's role may remain that of a passive listener. Thus individual counselling also tends to predispose patients to a compliance-based doctor-patient relationship, especially in the case of adolescent patients because of their relatively young age and frequent unwillingness to deal with their disease.

35 Feasibility of the PBL method

In the present study the PBL method, previously used in school and academic education, was adapted into the routine of our standard ambulatory clinic for diabetic adolescents and then compared with individual counselling method.

Participation

Judging from the excellent participation and the overall positive attitude to the time spent on clinic visits the education method was well accepted. With the exception of a few patients attendance at the education sessions was regular, absences being mainly due to examinations at school. The integration of the education program into routine clinic visits seems to be a well-functioning arrangement. A separate education program with frequent visits, like the one in the DCCT study, would most likely not work well because adolescents are often reluctant to take extra trouble for their diabetes. In the study by Tercyak and associates (1998) 43% of 99 adolescents refused the offer of an intensive therapy trial which required frequent visits, an increasing number of insulin injections and self-monitoring of blood glucose. The reasons for refusal were issues of convenience: increased clinic visits, transportation difficulties and concerns over the intensive nature of the treatment.

A considerable advantage seemed to be that the same group stayed together in this study; the participants learned to know each other and work as a group.

The case examples

The cases dealing with the daily problems of diabetes self-care functioned well for our program. Due to the 3 months' interval between the sessions, each case was resolved during the same session in which it was introduced at. However, it is likely that the same cases would function equally well in a separate diabetes education course or in a set-up allowing more frequent clinic sessions with take-home assignments for participants requiring them to gather information to be used to solve the problem in the next session. Each case included certain learning objectives, which were taken up in the discussions on that particular case.

The cases included in the learning sessions seemed for the most part to be interesting for the participants. Discussions often got off to an easy start as participants could identify with the cases and use their experience and expertise in solving theoretical problems.

There was little help available from the education booklets because it was difficult to find the information needed in them. Whenever there was a risk of misconception, the tutor as a health care expert was to intervene in the discussion. Occasionally the tutor might slip back into his or her former mode of teaching instead of stimulating the students to search for information and find a solution.

Advantages compared with the individual counselling method

In theory the PBL method offers many advantages in diabetes patient education in that it emphasises the students' own responsibility in acquiring knowledge and learning. A group learning situation provides students a chance of exchanging experiences and acting as resource persons for one another. The problems of every day diabetes self-care and the skills it requires offer an excellent ground for PBL. These are advantages which individual counselling lacks.

As tutors the nurse and the physician were able to acquire a multi-faceted view of the patients working in a group. It became clear that patients' attitudes towards diabetes and its care were revealed more intensively in the group setting than in individual counselling. This also became evident in the study by Schlundt and colleagues (1996), which used problem-solving in group sessions on diet education. Judging by the patients' perception of their own health, those in the PBL group seemed to be more relaxed than those in the individual counselling group. Probably due to support from others, the patients in the PBL group also seemed to have a more positive attitude towards diabetes, which would agree with medical students' more positive attitude to their studies in their PBL program as against conservative teaching (Kaufman and Mann 1997).

Possible disadvantages

There are, however, certain problematic aspects in the use of the PBL method in diabetic patients' education. One such is the patients' previous usually teacher-oriented and often compliance-based education. The patient may have been a passive partner in his/her own care and expects rules for daily treatment from health care personnel, and it may therefore be difficult for the patient to adopt decision-making from those hitherto regarded as authorities. In adolescence the parents also have a role in daily treatment, which may delay adolescents' independence.

Sensitivity and care are required of the tutors in discussions and interaction with patients. Tutors' attitudes may be authoritarian and paralyse the activity of the group, a

situation which may then be difficult to change. At times it would be desirable for the tutors to attend the sessions together to get each others' feedback.

Having experienced the patient-centred approach of their health care professionals, these patients may very well have difficulties in their doctor-patient relationships in the future in that the philosophy of empowerment is still catching up with health care.

Economic aspects

Patient education in adolescence has often been carried out in camps or on courses apart from clinic visits, this demanding extra resources. Thus patient education using the PBL method implemented in clinic routine is also financially worthwhile compared with most previous modes of intervention. In this study the PBL method was found to be time saving and thus more economical than individual counselling. If there is only one tutor per learning session, the saving is about a half of the price of individual counselling.

Evaluation of diabetes education methods

Evaluation of diabetes education interventions has been miscellaneous, often relying on such measures as patients' acquired knowledge of their disease or their level of glycosylated haemoglobin. The results have been conflicting. In the current study, as in other interventions (Korhonen et al. 1983), the scores on the knowledge test did not correlate with glucose control, something often seen in clinic practice as well. The reason may be that the knowledge test does not measure aspects of the management of diabetes self-care. A test which measures patients' problem-solving skills might be the most suitable for measuring how patients master their diabetes care, but rendering appropriate for the majority is a difficult task.

Because the goal of diabetes education is not only to provide the patient with knowledge and skills, but also to make him/her an active and responsible participant in diabetes care, it is important also to evaluate daily management, attitudes and perceived quality of life. The results are discussed below, along with the effect of the PBL method on glucose control and long term complications.

36 Effect of education

36.1 Management of daily diabetes care

Insulin

Adherence to insulin injection schedules seemed low according to answers to the question concerning omitting injections. At the transfer phase about 30% and at the end 40% reported forgetting an insulin injection at times. In fact, the actual adherence to an injection program among some patients might be poor continuously. In a study by Morris et al. (1997) there was evidence of nearly one-third of teenagers taking only two-thirds of their recommended dose of insulin throughout the year, and poor adherence to insulin treatment is suggested to be the major factor contributing to long-term poor glycaemic control in adolescence. In the current study, those with the poorest glucose control improved their glycohaemoglobin most. The most likely explanation for this is that forgetting insulin injections in reality decreased in spite of the opposite result. It may be difficult for the patient to confess neglect of insulin treatment, especially as regular injection is the issue most emphasised in patient education.

The reported amount of insulin U/kg body weight increased significantly during the study in both groups. In the multicentre study by Mortensen and colleagues (1997) adolescents at the age of sixteen through eighteen had a lower insulin dose/weight kg than our patients. The difference is probably due to better glucose control and with it better insulin sensitivity in Mortensen's study. In the current study those with better glucose control were taking a lower insulin dose compared with those with poorer glucose control.

Diet

Energy

In the current study there were no recommendations for calculated energy quantities but rather a recommendation for a diet appropriate for maintaining normal growth, normal weight and good glucose control. Thus energy intake is reflected in the outcome of diabetes management. However, no correlation was found here between the parallel HbA1c and the intake of energy or any other nutritional components in either of the

education groups, nor was there any correlation between BMI and energy intake. The growth of the boys and on the other hand the simultaneous attempts of the overweight girls to lose weight were probable confounding factors during the study.

The energy intake of diabetic boys was the same as in the study by Virtanen (1992), but that of diabetic girls was lower than that recorded by Pietiläinen (1995). In both studies the energy intake of healthy controls was smaller than that of diabetic girls and the same as in this study. In Virtanen's follow-up (1992) the energy intake of girls decreased as in the current study.

Carbohydrates

The intake of carbohydrates, about 46% of total energy, among the diabetic adolescents in this study was below the recommended amount, and even less than the amounts reported in other Finnish studies (Virtanen 1992, Pietiläinen 1995), which revealed levels from 49 to 50 E%. The difference may be due to the divergent ages of the study populations. Virtanen (1992) found in her follow-up that the intake of carbohydrates among diabetic adolescents decreased with age. In contrast, intake in the current study was unchanged. At transfer only few patients were able to calculate their carbohydrate portions and at the end of the study the situation still remained unsatisfactory, only a half of the patients, according to our knowledge test, mastering the calculation of carbohydrates. A principal reason for their poor learning seemed to be their belief that they did not need the skill because their eating habits remained the same from day to day.

Fat

In this study the intake of fat exceeded the recommendation in both education groups. Virtanen (1992) found that adolescents increased their fat intake with age, which is contrary to the present findings, according to which patients' intake of fat remained unchanged during the study. The most important source of saturated fat according to the diet diaries was cheese, and probably as a result of this the P/S ratio among girls decreased significantly in both education groups. The finding that boys with HbA1c < 8.5% had a significantly lower intake of fat compared to those with HbA1c ≥ 8.5% is consistent with the observations of Storlien (1996), who reported that increased insulin resistance correlated with a high fat diet.

Protein

The protein intake in the current study exceeded the recommendation, 1 g/weight kg, in both education groups, ranging from 1.2 to 1.3 g/weight kg, and remained at the same level during the study. An interesting finding in the PBL group was the higher protein content in the diet of those with microalbuminuria at the transfer phase when compared to those without. In the course of the study this difference disappeared. However, the content of protein in the diet of microalbuminuric patients still remained above the recommendation, as observed elsewhere (Toeller et al, Eurodiab IDDM Complications Study Group 1997).

Number of snacks

Snacks between meals have been considered necessary for insulin-treated patients (Ilanne-Parikka et al. 1999). Today this percept is less important in that patients are on multiple insulin injection therapy which allows increased flexibility in the timing of meals and the amount of carbohydrates consumed. The omission of snacks increased during the study, especially among the boys, illustrating a growing identification with their non-diabetic peers, who generally take fewer snacks (Virtanen 1992).

In summary, nutrition education in this study mainly resulted in maintenance of the prevailing diet, with only very small signs of dietary improvement. Nutritional components in the diabetic adolescents' diet do not match the current diet recommendation. The fat content is higher and carbohydrates lower than recommended. The protein content of energy remained too high, especially in microalbuminuric patients. Although the adolescent diabetic patients received diet education at almost every clinic visit, their diet remained worse than their healthy peers' in an Eastern Finland population (Vartiainen et al. 1996). While the diet of the Finnish population has improved during the last few years, that of diabetic adolescents has not. This coincides with a report of only modest, usually temporary dietary changes in diabetes nutrition interventions in a review article by Koivisto-Hursti and Sjöden (1997). Judging from the constancy of the diet maintained by the patients in the current study, it would appear difficult to change dietary habits through group or individual education. One reason for failure may be that these subjects still live at home with their parents, who take care of the food in the family and carry out diabetes diet according to the education they have themselves previously received. For instance in the eighties the recommendation on protein use was more broader than later. It might be useful to educate parents while their children are still adolescents, and the adolescents later when they are moving from home.

Exercise

At the transfer phase 60% of the patients in the PBL and 65% in the control group reported exercising at least every other day, according to the recommendation (Koivisto et al. 1995). The frequency of exercise did not increase during the study, although the advantages of regular exercise were emphasised both in the education session on exercise in the PBL group and in the individual counselling in the control group. In this regard neither one of the methods was effective. Huttunen and colleagues (1989) were likewise unable to find an increase in motivation even in group exercise. The older the participants in their study, the more they neglected exercising. In Finland the total physical activity among young people decreases during adolescence down to the level of adulthood (Fogelholm 1998). Typical of adolescent development is clumsiness and a difficulty in perceiving one's body by reason of rapid growth, and not infrequently young people are unwilling to exercise. Another reason for the declining interest in exercising in adolescence might be the fact that school becomes more demanding with age.

In this study glucose control was no different among those who exercised according to the recommendation from those who did not. In the above-mentioned study by Huttunen and group (1989) physical fitness increased as assessed by $VO_{2\,max}$ with regular weekly training, but glycaemic control worsened.

Home tests

All patients had tools for self-monitoring of blood glucose, but at the end of the study only 77% of the PBL group and 81% of the control group reported using self-monitoring of blood glucose (SMBG). The number of those who used SMBG did not increase significantly, but the test frequency of those who used it increased. Groups under Anderson (1997) and Wysocki (1996) found that neglect of SMBG increased with age while parental involvement enhanced adherence to SMBG. In the present study only a few parents participated in SMBG. Data in epidemiological studies of the test frequency of adolescent patients remain scant. Virtanen (1992) found that 11% of adolescent patients neglected SMBG totally, which agrees with the present finding.In a study by Evans and associates (1999) from Tayside, England, it was found that over an 18-month period only 50% of the teenage group studied ever even obtained testing strips. However, in those obtaining blood testing strips regularly there was a clear correlation between glycaemic control and frequency of testing. In a study by Dorchy and colleagues (1997) reporting adolescents making 111 ± 27 measures per month, the number of SMBG correlated inversely with HbA1c. The patients were younger than those in this study,

and most likely in their parents' care. In our study a correlation was also found between HbA1c and frequency of SMBG even from the level of 10 tests per month at the end of the study, but not at the transfer phase. This proves that in the course of the study the young patients had learned to utilise their test results. While fabrication of the diaries on self-monitoring was occasionally suspected, the patients were only informed about the discrepancy between the test results and HbA1c. There was no difference between the two education methods in the frequency of SMBG.

36.2 Glucose control

Glycohaemoglobin A1c

Even though glucose control improved in both the PBL and the control group, the glycohaemoglobin A1c level remained higher than in the DCCT study. However, the respective study programs differed. The present study was population-based, while in the DCCT study the patients were highly selected and did not evince psychological problems. During the first year the patients in the DCCT study had as many clinic visits as the total in the present case. In addition there were frequent telephone contacts during the intervals in the DCCT study.

The purpose of the DCCT study was to evaluate the development of short- and long-term complications in intensive diabetes treatment, while the aim here was to apply and examine a new educational method as a tool in diabetes education.

Comparing the HbA1c results with those of the control group of the DCCT study, the effect of education in the current study is evident. Lacking education, the control group in the DCCT study remained under the same poor glucose control. The frequency of their clinic visits was the same as here. The same can be seen in a prospective cohort study by Orr and colleagues (1996); diabetic adolescents remained in a poor glucose control after transfer from a paediatric clinic. Mortensen and Hougaard (1997) found that HbA1c increases in both sexes with maturation.

The improvement in glucose control was significant among those with poor glucose control, HbA1c > 9%, at the transfer phase. Those with the poorest glucose control are the adolescents who neglect their insulin treatment most (Morris et al. 1997). One may assume that as a result of education the patients with poor glucose control changed their attitudes towards diabetes and also improved their self-treatment.

Although the improvement in HbA1c in this study was far from that in the DCCT study, the result would seem to be clinically significant. Danne and colleagues (1994) in

their Berlin Retinopathy Study found a significant difference in the prevalence of retinopathy between HbA1c categories under and over 9%. Krolewski and group (1995) suggest that a glycaemic threshold for retinopathy and microalbuminuria exists at an HbA1c level of 8%, with no further appreciable reduction in risk below this level. However, DCCT (1996c) questioned this and concluded that there is no HbA1c threshold value for microvascular complications, and that the reduction in the risk of complications is continuous. Orchard and colleagues (1997) agreed with the notion of a linear risk decrease in accordance with HbA1. In adolescence puberty may be a confounding factor increasing the incidence of microvascular complications (Kostraba et al. 1989, Nishimura et al. 1998).

The levels of several known risk factors for atherosclerosis were significantly lower in the group with HbA1c ≤ 9% compared with those with HbA1c > 9%. Glucose control was poor at the transfer phase, the girls having a higher HbA1c than boys, which is a typical finding for this age group (Salmi 1989, Orr et al. 1996, Mortensen et al. 1997). Insulin resistance is considered to be a reason for poor glucose control in adolescence. Self-treatment in adolescence also tends to be difficult because of young people's need to be like their peers and their neglect of treatment is usual. Girls' poorer glucose control versus boys' has been explained by earlier onset of puberty and switch of interest to other subjects but diabetes. In this study all the girls experienced menarche before transfer. Their self-treatment did not differ from that of the boys.

Interesting in the present study was the equal glucose control in boys and girls when the girls with an eating disorder were excluded. In spite of numerous investigations of eating disorders among girls, there have been no epidemiological studies clarifying the effect of eating disorders on glucose control. Affenito and colleagues (1997a) point out that poor HbA1c may be clinically useful in identifying eating disorders among females with IDDM.

The fact that there was no difference in HbA1c between the education groups is probably due to many factors influencing glucose control. The heterogeneity of the diabetic subjects was probably the most important cause. In the PBL groups an increase in motivation was seen several times simultaneous with a decrease in HbA1c values in nearly all members of the group. Even if working in a group seems in many ways beneficial, it should be borne in mind that there are always patients who do not like being in a group, and who would derive greater benefit from individual counselling. This, however, cannot be taken into consideration at randomisation.

Severe hypoglycaemia

Comparison of the frequency of hypoglycaemia here, 16% of the patients reporting one or more episodes, with that in other studies is difficult by reason of the varying age of patients throughout these studies and their use of different definitions of severe hypoglycaemia. In a study by Bhatia and Wolfsdorf (1991) the frequency of severe hypoglycaemias was lower than here, most likely due to their tighter criteria for severe hypoglycaemia, while according to Limbert and colleagues (1993) the frequency was higher, 44% of diabetic adolescents suffering severe hypoglycaemia. Davis and associates (1998) found an increasing incidence of hypoglycaemia with improving glucose control over four years, which agrees with the present observations. The same was seen in the DCCT study which found severe hypoglycaemia requiring assistance or a hypoglycaemic coma or seizure occurring in 81% of the adolescent patients in the intensive treatment group and in 44% of the patients in the conservative treatment group. The rate per 100 patient years was 27.8 events (DCCT 1994). In the DCCT study glucose control was markedly tighter than in other studies. In the current study the rate of severe hypoglycaemia was 20.8 events per 100 patient year.

In the present study those reporting severe hypoglycaemic events had a lower insulin dose/body weight and mean HbA1c, a decrease in insulin dose during the study vs. an increase as compared to those without hypoglycaemic events. The lower, and during the study decreasing insulin dose in those with severe hypoglycaemia is a logical finding pointing to their higher insulin sensitivity in comparison with subjects without severe hypoglycaemia. Elsewhere the insulin dose has been similar in those with and without severe hypoglycaemia (Bhatia and Wolfsdorf 1991, Limbert et al. 1993) or higher in those with severe hypoglycaemia (DCCT 1991). Most other studies have revealed no difference in mean HbA1c between those with and without severe hypoglycaemia (DCCT 1991, Bhatia and Wolfsdorf 1991, Limbert 1993), although the last-mentioned investigators found a significantly lower level of HbA1c at the clinic visit closest to the reported episode. Daneman and colleagues (1989) agree in finding a lower HbA1c throughout their study in those with severe hypoglycaemia. It has been shown that poor glucose control contributes to an upward shift in the glucose threshold for counter-regulatory hormone release and in symptom awareness during mild hypoglycaemia (Jones et al. 1991). This may explain why the frequency of episodes of severe hypoglycaemia was lower in those with poor glucose control.

In the present study the bouts of severe hypoglycaemia occurred in several patients within a short time span. This supports the theory of a lowered blood-brain threshold for glucose and diminished perception or unawareness of hypoglycaemia under tight metabolic control (Mokan et al. 1994). Impaired counter-regulatory hormone response

to hypoglycaemia has also been revealed in children and adolescents (Hoffman et al. 1994). The awareness of hypoglycaemic symptoms may be improved by an interval of strict avoidance of hypoglycaemia (Dagogo-Jack et al. 1994). In practice, counselling of the patient after an episode of severe hypoglycaemia is important. It often seems difficult for the patient to reduce the insulin dose despite severe hypoglycaemia as the fear of deterioration of glucose control may be out of proportion. In the present study there were three girls each of whom had five events of severe hypoglycaemia. They all took excessive and extra insulin doses without measuring blood sugar or injected short-acting insulin without a meal. On the other hand, a decrease in insulin after severe hypoglycaemia may easily be excessive, leading to a worsening of glucose control (Tupola et al. 1999). Wredling and colleagues (1992) found that patients prone to severe hypoglycaemia were more anxious and had a decreasing sense of well-being. Here no difference emerged in the quality of life, depression or personality between those with and without severe hypoglycaemia. This is consistent with the nature of adolescence with its challenges and interests.

Most of the outsets of severe hypoglycaemia took place during sleep. The events occurred either in the morning at the time of awakening, or when the patient had already awakened, taken an insulin shot, had breakfast and then gone back to bed, only to be found unconscious a couple of hours later. In at least six cases (17%) alcohol had been also consumed the previous evening. Bhatia and Wolfsdorf (1991) found alcohol to be the main predisposing factor in 18% of cases. In a study by Limbert and associates (1993) in only two (6.2%) of those with severe hypoglycaemia had alcohol been a contributing factor.

A treatable cause of hypoglycaemia was found in three out of four of these events. Most often the patient's error had been to go to bed after injecting short-acting insulin or taken too high a dose of intermediate insulin the evening before while doing exercise, disco dancing, drinking alcohol etc. The finding of treatable reasons is equally common in other studies (Tupola et al. 1998b, Limbert et al. 1993, Bhatia and Wolfdorf 1991).

Regular measurement of blood sugar every morning, at least, was emphasised as the minimum frequency of SMBG for avoiding hypoglycaemia. Lopez and colleagues (1997) found low or very low blood glucose concentrations before breakfast to be related to a higher risk of nocturnal hypoglycaemia.

Severe hypoglycaemia is a frequent acute complication of diabetes in adolescence associated with insulin dose, glucose control and hazardous self-treatment. In most cases severe hypoglycaemia is avoidable by meticulous self-care, which requires sufficient patient education. It is difficult to arrive at judgements of educational methods in teaching hypoglycaemia from the present study, because of the three girls, one in the PBL group and two in the control group, who had an aberrant attitude towards insulin treatment

with recurrent hypoglycaemia. Another reason is the late introduction of the topic "hypoglycaemia" in our education schedule. In the light of this study, when the responsibility for diabetes treatment is shifting from parents to adolescents, it might be advisable to deal with hypoglycaemia at the beginning of the education program to obviate the risk of severe hypoglycaemia.

36.3 Attitudes and responsibility of patients

When the patients in the PBL group were compared to those in the control group and the healthy peers at transfer, no difference could be found in patients' perception of their health. However, at the end the control group perceived their health as significantly poorer than the PBL group and the healthy peers. While in a survey by Rimpelä and group (1997) of 8,382 Finnish adolescents of 14 through 18 years of age 36% of the boys and 27% of the girls perceived their health as excellent; in the present study the percentage of those who perceived their health as excellent was lower in both groups as well as in healthy controls. However, at the end of the study the percentage of those who perceived their health as satisfactory or poor was similar in the PBL group, among the healthy controls and in the study by Rimpelä's group, but in the control group the corresponding percentage was significantly higher.

Why the members of the control group perceived their health as poorer than those in the PBL group and the healthy peers, is not clear. The groups differed in schooling, but their perceptions of their health were similar whether they were attending high school or vocational school. Depression and sense of the quality of life, which may be reflected in the assessments, did not differ between the PBL and the control group at the end of the study. One explanation may be the difference in educational methods. In the group sessions the participants could recognise the others as ordinary peers in spite of their diabetes and this may have tendered their perception more positive in comparison with the control group. The patients in the control group had no contact with other diabetics within the clinic routine. Young diabetic patients may easily feel estranged from healthy peers on account of the many restrictions their diabetes imposes during childhood.

The inquiry into "locus of control" was introduced only at the end of the study, and therefore conclusions as to the effect of the education period on it are difficult to draw. The internal locus, according to which the patient himself has control of his life, is considered to be a goal in diabetes education. Moffat and Pless (1983) have shown that it is possible to change patient's attitude in the direction of an internal locus.

In the present study no difference was found in internal locus between the PBL and the control group. However, the patients in the control group evinced a significantly

stronger external locus than the members of the PBL group. This is in harmony with the philosophy of PBL education which emphasises one's own responsibility.

HbA1c correlated with external locus, which is consistent with the finding of Brown and associates (1991). A group under Lernmark (1996) found the external locus of control to be associated with hospitalisations, emotional problems and high HbA1c levels among adolescent diabetic boys. In the present study no difference in this aspect in regard to gender was found. This again diverges from the results of Hamburg and Gale (1982), who found that the boys with external and girls with internal locus had good glucose balance.

When the patients and their parents assessed the impact of self-care on a scale of 0 to 10, the scores did not differ from one group to another at the transfer phase, but at the end the parents of the PBL group had significantly lowered their scores. This difference may be a sign of patients' greater independence in diabetes self-care in the PBL group; the parents were presumably not allowed to participate in the treatment as actively as in the control group. The correlation of the scores between patients and parents at the end in the control group, but not in the PBL group, would support such a conception.

The groups did not differ in their estimation of the impact of diabetes on their future health. The number of those who thought that their health would improve in the future, altogether about a quarter of the adolescents, was surprisingly high. This raises the question of the patients' understanding of the seriousness of the disease, in other words, is the picture of diabetes given to adolescent patients unrealistic? According to a study by Standiford and associates (1997) diabetic adolescents aged 10 to 17 years understood that diabetes is a life-long disease, but they were optimistic about a cure in the future. Leung and colleagues (1997) found diabetic adolescents' perception of the severity of diabetes to be lower in comparison to clinical indices estimated by physicians.

The cure of diabetes in the future is the topic repeatedly brought up by patients. Obviously the estimations of the parents were more realistic. The education period did not change anticipations significantly in either group.

The questionnaire concerning the most important goal in diabetes self-care revealed a need to be like peers, which is typical of adolescent development. Good glucose control was also high in importance, and among the parents it was the number one alternative chosen from the start of the study.

The significance of questionnaires such as these lies in the way they provide health care personnel with important information and understanding of how the young diabetic patients view their illness, which in turn may be helpful in efforts to individualise their education and treatment.

The foregoing results give some indication that the PBL method may exert a positive effect on diabetic adolescents' attitudes. The young people attending the PBL program

had a more optimistic picture of their health and relied less on the health care personnel than did the control group. One may assume that the patients' sense of responsibility, emphasised in the PBL method, will also result in their developing a responsible and independent role in their diabetes self-care.

36.4 Social function

Personality

The only significant change in personality inventory during the study was in the scores measuring anxiety. Anxiety scores, assessed by one question, increased significantly in the control group, but not in the PBL group. The difference may be explained by the different education methods. In the PBL group the members derived support from each other, which was not possible in the control group. Kyngäs and Hentinen (1995) described a group of young diabetic adolescents who were not motivated to comply with a self-care program and who found self-care useless, and furthermore, felt that they had received no encouragement. Such patients may become anxious when they receive information on diabetes. One of the diabetic group's contributions is raising and maintaining patients' forward-looking attitudes.

A logical result at the end of the study was higher scoring on social activity, dominance and selfishness among those with better glucose control when compared to those with poorer. The difference was found only in the control group. The fact that no such finding was recorded in the PBL group may reflect the influence of the group; the members felt accepted regardless of diabetes control.

An interesting finding at the transfer phase was the difference between the diabetic adolescents and healthy peers in scores on a few traits of personality. Scores characterising a higher sense of responsibility, lower need of variety, lower impulsiveness and flexibility in the PBL group, are consistent with the concept of strict adherence to a diabetes treatment schedule, and possibly the control of the parents.

At the end, the diabetic adolescents in the PBL group differed from the healthy controls only in lower scores for openness, self-confidence and impulsiveness, a finding which is in keeping with the nature of diabetes and its treatment. In the control group no difference was found at the end of the study between the diabetic adolescents and the healthy controls in any trait on the personality scale. These results show in a convincing way that most diabetic adolescents have acquired resolution in diabetes self care and their attitudes are close to those of healthy peers. In earlier studies the self-esteem of

young diabetic people has been found to be lower than that of their healthy peers (Jacobson et al. 1997b, Lloyd et al. 1992b).

Smoking

The number of smokers increased during the study. Especially boys in the PBL group started smoking. The prevalence of smokers is consistent with a Finnish study of young people, which reported 29% of students in the ninth grade in basic school smoking (Rimpelä et al. 1996). Kokkonen and Paavilainen (1993) found a frequency of smoking in young adults of about 30%, at least half smoking 10 or more cigarettes daily. According to their study diabetic patients smoked most frequently among patients with a chronic disease and more than healthy controls. In the DCCT study (1994) only 0-5% of adolescents smoked at baseline, which reflects the high motivation and selection of the patients.

In previous studies smoking has been associated with poor glucose control (Lundman et al. 1990, Kokkonen and Paavilainen 1993, Chaturvedi et al. 1995). Here in contrast, no difference in HbA1c or in HbA1c change was found during the study between the smokers and the non-smokers in the PBL or in the control group. The smokers exercised to the same degree as non-smokers, but their blood glucose self-monitoring was less frequent. Lundman (1990) found that smokers and non-smokers differed very little in several assessments measuring psychological well-being and attitudes towards the disease and its management. In the current study the smokers did not differ from the non-smokers in scores measuring quality of life or depression.

In Finland smoking is common among young people. By reason of the urge to identify with peers, it is not easy to prevent smoking among diabetic adolescents unless general health education succeeds in reducing smoking at teen age. However, antismoking education is important at a diabetic clinic and seems to have an effect on adolescent girls.

The PBL education method was not successful in preventing an increase in smoking. It may be suggested that people in a group did not feel antismoking education threatening.

Alcohol use

The frequency of use of alcohol increased significantly in the present study in both genders in both the PBL and the control group. According to Virtanen (1992), diabetic adolescent males used alcohol seldom and females not at all. The difference is probably

due more to the method of assessment than to a change in culture. The frequency of users in the current study seems less than among healthy peers as reported by Rimpelä and colleagues (1996), where was no difference in the frequency of alcohol use between boys and girls, but frequency of users in vocational school was higher than in high school. In our study the frequency was similar, but the alcohol consumed was stronger in vocational school than in high school.

Teen-age drinking is often perceived by society as normal experimental behaviour and not all drinking by adolescents is seen as hazardous. Adolescents may nonetheless be at an increased risk of becoming intoxicated because of their limited experience of alcohol and their smaller body size. Diabetic subjects especially are in danger from the hypoglycaemic effect of alcohol (Puhakainen 1991). In the present study alcohol was a contributing factor in at least six of the cases of severe hypoglycaemia.

At the end of the study all girls and 80% of the boys reported using alcohol at least sometimes. It is obvious that the present-day permissive attitude towards alcohol and young people's need to identify with peers have a strong effect on diabetic adolescents' alcohol use. Such an attitude also emerged in group discussions. Discussion of alcohol in a group may be embarrassing for those members who have not used alcohol when the group includes an individual who has experimented with great amounts and boasts of his experiences. Such situations can make even those with only modest experience feel encouragement to drink.

During adolescence restriction of alcohol seems difficult. Here neither of the education methods in the present study was effective. An appropriate goal in diabetes education would be guidance in the hazards of heavy alcohol use.

36.5 Psychological health

Quality of life

In many studies psychological problems have correlated with poor glucose control and long-term complications (Lloyd 1992a, Blanz et al. 1993). In the present study no correlation was found between DQOL (quality of life) scores or any of its sub-scales and HbA1c, microalbuminuria or retinopathy. Guttmann-Bauman and co-workers (1998) found by DQOL that diabetic adolescents in better metabolic control reported better quality of life. Although one would expect the intensification of diabetes treatment to have resulted in an increase in stress, the scores describing diabetes-related worry decreased. The educational method was not crucial. From the point of view of health care

personnel and parents, it is encouraging that diabetic adolescents' perceived quality of life was similar to that of healthy peers, indicating good adjustment to their disease.

Depression

The frequency and degree of depression were different at the transfer phase between the PBL and control group, but similar among diabetic subjects and their healthy peers at the end, and did not correlate with diabetes control or complications. It is probable that in mid- and late adolescence there are other areas, for example sexuality and personal appearance, which influence the maturing phase and are perceived as more important than a chronic disease (Rickert et al. 1990). There were two exceptions; a boy with recurrent ketoacidosis, the state associated with psychiatric difficulties, as described by Tattershall (1985), and a girl attempting suicide with insulin, a case type known from diabetes practice and case reports (Kaminer 1988).

Eating disorders

In the present study the frequency of eating disorders among the girls was 15%, which is comparable with the 9% observed by Rodin (1992). Poor glucose control is typical of girls with an eating disorder (Polloc 1995, Affenito et al. 1997b) as was also seen in this study.

36.6 Physical health

Height and weight

The mean height of healthy boys in Finland at the age of 18 years in the year 1995 was 180 cm and of girls 167 cm (Rimpelä et al. 1997). In the present study the diabetic boys, with a height of 179.3 cm reached the mean of their healthy peers, while the diabetic girls remained shorter, 163.2 cm. A risk factor for retarded height in diabetic adolescents is unsatisfactory glucose control (Mortensen 1997).

Both those who grew and those who had finished growing increased their weight, the girls who had ended their growth most. The mean BMI of the girls here, 24 kg/m^2, is in line with the 85% percentile of healthy girls considered a risk for getting fat (Rimpelä et al. 1996a). The boys' BMI is in the 50% percentile. According to a study by Domargård

and colleagues (1999), Swedish diabetic girls and boys at the age of 18 had the same BMI as in the current study. In the DCCT study (1994) the development of overweight was significant; at the end of the study 48% of adolescent patients under intensive treatment were overweight in spite of the fact that those who were overweight at baseline were excluded from the analysis. According to the same criteria for overweight, 3% of our patients were overweight at transfer and 5% at the end of the study.

Several authors (Gregory et al. 1992, Virtanen 1992, Pietiläinen et al. 1995) have found overweight in diabetic adolescents, especially among girls, as was the case in the current study. Adolescent patients prone to overweight seem to maintain their previous eating habits after the end of growth, and it is therefore important to check carefully diabetic patients' energy intake when their growth is ending. Although the diet education in the PBL group was more practical compared with that in the control group, there was no difference between the groups in BMI development. Four girls with an eating disorder in the PBL group might have constituted a confusing factor. Obesity is also a somewhat too intimate topic to discuss in a group, especially in adolescence.

Lipids

The only change in this study was seen in the HDL cholesterol of the boys, which decreased by 7.5%, obviously for physiological reasons (Cruichanks 1985).

The total cholesterol values at the end seemed lower than those in a previous Finnish study (Virtanen 1993), but higher than in the study by Cruichanks (1985), and also higher in girls when compared to healthy girls in Eastern Finland (Vartiainen 1996). In the DCCT study values of total cholesterol in diabetic adolescents were higher and HDL-cholesterol lower than in our study even when patients with hypercholesterolemia had been excluded (DCCT 1992).

Virtanen found no difference in cholesterol level between boys and girls, but here as in other studies (Cruickshanks et al. 1985, DCCT 1992), cholesterol in girls was significantly higher. In summary, the lipid values of diabetic adolescents seemed higher than those of healthy peers, but lower compared with those reported in previous studies. During the study cholesterol values had a tendency to decrease, but neither of the education methods seemed successful in lowering the values to the level of healthy peers.

Long term-complications

Nephropathy

Microalbuminuria

The prevalence of persistent microalbuminuria, 10%, in this study, is comparable to that reported by Widstam-Attorps (1992) and Quattrin and colleagues (1995). Those studies, however, were not population-based and the patients in the first were heterogeneous by age and the duration of diabetes shorter. In a study by Janner and associates (1994), 20% of diabetic adolescent patients had developed persistent microalbuminuria during a mean follow up of 4.6 years.

High HbA1c has been found to be a risk factor for microalbuminuria (Schultz et al. 1999). Rudberg and Dahlquist (1996) found that microalbuminuria frequently normalised in adolescents and this was associated with better prevailing metabolic control, younger age and lower diastolic blood pressure. In the present study the decrease in HbA1c probably retarded the incidence of microalbuminuria. According to the DCCT study a decrease of 10% in HbA1c means a decrease in complications by 21–49% (DCCT 1996c). In the current study glucose control was similar in the PBL and in the control group, which may explain the similarity of frequency of microalbuminuria in the two groups. Although many risk factors underlying the development of microalbuminuria have been documented in previous studies, only evidence of microalbuminuria and retinopathy at transfer were predictive factors for the development and progression of microalbuminuria, an observation in agreement with that of the The Eurodiab IDDM Complications Study Group (1994).

The association of poor glucose control and hypertension with microalbuminuria, found in the current study has been documented in many studies (Quattrin et al. 1995, Sochett et al. 1998).

This study revealed an association between increased protein intake and microalbuminuria, as was also found in the epidemiological Eurodiab study (Toeller et al. 1997). Earlier studies have shown that decreased protein intake reduces microalbuminuria (Pedrini et al. 1996). In practice, however, the estimate of protein content in diet from diaries is prone to miscalculation.

Barzilay and associates (1992) showed that a positive family history of hypertension was both associated with and predicted diabetic nephropathy and hypertension. The present results support the conception of a tendency towards nephropathy and hypertension as genetic in that there was a significant difference in family history of hypertension between the groups; 67% of those with persistent microalbuminuria had one par-

ent with hypertension vs. 19% of the normoalbuminuric patients. The diabetic patients with a family history of hypertension may be predisposed to microalbuminuria and form a special group needing effective patient education.

Retinopathy

The frequency of retinopathy in this study would seem to be in line with the Finnish population-based study by Falck and group (1993) in diabetic adolescents. In one other Finnish population-based study, that by Kokkonen and associates (1994a), retinopathy seemed to progress in adolescence. In the present study the frequency of retinopathy increased only marginally. The duration of diabetes was here the variable which was associated significantly with retinopathy. This is in harmony with other findings (Goldstein et al. 1993, Falck et al. 1993, Bonney et al. 1995, Kokkonen et al. 1994, Donaghue et al. 1997). Falk's group (1993) found a higher frequency of retinopathy in girls. They concluded that the gender difference was due to the poorer glycaemic control in the girls. Here no gender difference in retinopathy was found, and glycaemic control was similar in those with and without retinopathy. Elsewhere poor glycaemic control has been associated with retinopathy (Kokkonen 1994a, Bonney 1995). The missing association of retinopathy and glycaemic control in this study may be a result of different factors. Retinopathy is rare before puberty (Kostraba 1989, Falck 1993,) and our patients, especially boys, were still near puberty. Also the improvement in glucose control during the study may be a confounding factor. It has been shown that a tightening of glucose control may result in a transient worsening of retinopathy (Dahl-Jorgensen et al. 1985), or microaneurysms may be found to have disappeared (Bonney 1995, d'Annunzio et al. 1997). The DCCT (1995b) showed that intensive therapy, which resulted in good glucose control, had a beneficial effect on retinopathy, which did not begin sooner than 3 years after the improvement.

According to the present findings retinopathy in adolescence was mild and microaneurysms might disappear. No predictive factor was found for the development of retinopathy.

Special attention should be directed in patient education to diabetic adolescents with a long duration of diabetes and poor glucose control, which factors seem to be associated with retinopathy.

Autonomic neuropathy

In this study deep breathing and handgrip test seemed to be the most reliable of the tests in the case of diabetic adolescents by reason of their high correlation between the first

and the second test. Lewitt and colleagues (1996) recommended the Valsalva manouver as best for detecting longitudinal progression of autonomic neuropathy because of the small variance ratio in repeated measures. Only a few random pathological test results were noted in the current study, which did not fulfil the criteria for diagnosis of autonomic neuropathy (Piha 1989).

The results here are not consistent with those of other studies (Verrotti et al. 1996, Young et al. 1986), where autonomic neuropathy was found in 18 to 28% of diabetic adolescents. The results of the autonomic test battery in diabetic adolescents are controversial, and diagnosis of neuropathy is unreliable. Signs of neuropathy seemed to be minimal and according to this study did not progress during the period of two years.

37 Achievement of educational objectives

An educational goal in the present study was to help the patients become independent and both psychologically and socially healthy people who would take the responsibility for their diabetes and attain to optimal diabetes control.

While the patients in the PBL group assessed their health as comparable to that of their healthy peers, those in the control group estimated their health as poorer than did the PBL group and the healthy peers. Judging from the PBL group's assessment of their own contribution in the diabetes course, these patients also seemed to be more independent of their parents than those in the control group. Their psychological well- being was similar to that of healthy peers, although anxiety increased in the control group during the study. In self-evaluated personality the PBL group evinced only a few traits different from those of their healthy peers but not from the corresponding traits in the control group. The diet recommendations were not achieved, but the proportion of seriously overweight patients remained low. Self-monitoring of blood glucose increased but still remained too scarce. Smoking and use of alcohol became as frequent as among healthy peers, illustrating the need for identity. Both groups achieved the same improvement in glucose control, which was one of the most important goals of the study. The frequency of nephropathy remained the same, but retinopathy marginally worsened. In conclusion, the educational goals were reached in many respects and the PBL method proved to be a feasible and economical educational method.

SUMMARY AND CONCLUSIONS

Adolescence is the period of development when young people create their own personalities and integrate a chronic disease into their lives. It is also the time when young people become independent and adapt their diabetes management into their everyday routines.

The present study was the first population-based educational study of diabetic adolescents at the transfer phase from the paediatric to an adult medical clinic. A group education method, Problem Based Learning, which had not previously been used in structured patient education, was implemented in an ordinary diabetes clinic operation. One educational goal was to provide diabetic adolescents with knowledge and skills needed in their everyday care and to help them become motivated, independent and both psychologically and socially healthy people who would take responsibility for their diabetes and attain to optimal diabetes control.

The aims of the study were to investigate feasibility and effect of the Problem Based Learning method in diabetes patient education. The PBL method was compared with conservative individual counselling, a practice generally used in health care. The study population comprised 86 diabetic adolescents aged 16.7 (SD 0.5) years with diabetes duration 8.4 (SD 3.8) years, who at transfer from paediatric to adult medical clinic were paired by matching them by gender and duration of diabetes. The pairs were then allotted to two groups. In the study group patient education was implemented using the Problem-Based Learning method and in the control group by individual counselling. The education was carried out in a program of nine diabetes-related topics in 10 routine ambulatory clinic visits during a period of 2 years.

The written cases used in the PBL method worked well in most of the learning sessions which were seldom missed by the patients. Generally the reason for absence was school. Four patients in the PBL group dropped out for various reasons.

The Problem Based Learning method proved effective. In diabetes self-care the adolescents' independence of parents grew, the frequency of their blood glucose self-monitoring increased, and in their diet they were making changes to meet the recommenda-

tions at least to some extent. Glucose control in the PBL group improved significantly from HbA1c 10.3 (SD 1.8)% to 9.3 (SD1.5)% and an equal improvement took place also in the control group. The frequency of severe hypoglycaemia, 20.8 cases/100 patient year, is comparable with that of other studies. The BMI of the patients increased with their growth during the study, but the number seriously overweight remained low. Of incipient microvascular complications nephropathy as microalbuminuria was found in 10.2% and retinopathy in 21.4% of the patients. The frequency of nephropathy remained the same, while retinopathy marginally increased to 30%. No worsening of autonomic nervous function could be seen in the tests. There was no difference between the PBL and the control group in microvascular complications. While the patients in the PBL group assessed their health as comparable to that of their healthy peers, those in the control group estimated their health as poorer than did the PBL group and the group of healthy peers. Judging from the PBL group's assessment of their own contribution in the diabetes course, these patients also seemed to be more independent of their parents than did those in the control group. The perceived quality of life, assessed in inquiries modified from the DCCT, did not differ from that of the healthy peers in either of the education groups, although anxiety increased in the control group during the study. While according to Beck´s inventory about 20% of the patients were depressed, the frequency and severity of depression was similar to that of healthy peers. In self-evaluated personality the PBL group showed only a few traits different from those in healthy peers but not from the corresponding traits in the control group. At the end of the study the conception of one's capacity to control diabetes (locus of control) differed in the respective groups, the patients in the control group being more externally oriented than those in the PBL group.

While smoking in the PBL group increased, especially among boys, the control subjects remained unchanged in this respect. Use of alcohol increased in both groups. These adverse phenomena can be seen as part of the diabetic adolescent's need to identify with healthy peers. This need was also evident in the survey of the patients' attitudes towards diabetes and its treatment.

The PBL method requires less time than was spent in the individual counselling method, which makes it more economical.

In all, the educational goals were reached in many respects and the PBL method proved to be a feasible and economical educational approach, and therefore recommendable for patient education in clinical routine.

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11.8 Education interventions in diabetic adolescents (years 1978–1999)

Author (country)	Type of intervention and strategy	Context of intervention	Sample characteristics	Study design	Effect
Lebovitz et al. 1978 USA	Enhanced education techniques of self-management	summer camp 2 weeks	n=111 average age 12 yr per cent female 53	single group	Knowledge compliance increased
Grand-guillaume 1979 Switzerland	Diet instruction low cholesterol diet	outpatient clinic 4 yr. 16 sessions 1.5–2hr each	n 33 average age 12 yr	single group	Cholesterol reduced
Galatzer et al. 1982 Israel	Counselling crisis intervention to reduce future psychosocial maladjustment and improve compliance	outpatient variable duration	n 223 average age 25 yr per cent female 50	control group	Compliance and sociability increased
Moffat et Pless 1983 Canada	Enhanced education enhanced locus of control	summer camp 3 weeks	n 186 average age 12 yr per cent female 47	control group	Internal locus of control enhanced
Rose et al. 1983 Canada	Relaxation training anxiety management training	outpatient clinic 7hr in 2 weeks home practice 5 months	n 5 average age 17 yr per cent female 100	single group	Control of stress and anxiety enhanced
Campaigne et al. 1985 USA	Exercise instruction in aerobic fitness	outpatient clinic 3 sessions 45 min each weekly/12wk	n 14 average age 16 yr per cent female 57	control group R	Physical fitness enhanced

Kaplan et al. 1985 USA	Social learning intervention	summer day school 3 weeks 3 hr daily	n 21 average age 14 yr per cent female 62	control group R	HbA1 decreased
Lucey et al. 1985 UK	Didactic education Program to increase overall knowledge	outpatient two visits 6 hr each	n 49 average age 12 yr per cent female 50	control group	Knowledge Compliance increased
Wilson and Endres 1986 USA	Self-monitoring training instruction in use of blood glucose meters	outpatient clinic: home 12 weeks, out-patient visits at 3 week intervals	n 18 age 12–18 yr. per cent female 55	single group	HbA1 decreased
Belmonte et al. 1988 Canada	Self-monitoring of blood glucose	outpatient clinic visits 3–4/year 3 years	n 219 38 per cent 12–16yr, 22 per cent > 16 yr per cent female 48	single group	HbA1=
Marrero et al. 1988 USA	Home exercise program	outpatient clinic 45 min x3/wk 12 weeks	n 10 average age 13 yr per cent female 40	control group R	Aerobic fitness increased HbA1 decreased
Anderson et al. 1989 USA	Enhanced education	outpatient peer group 18 months	n 70 average age 13 yr per cent female 53	control group R	HbA1 decreased Use of SMBG increased
Huttunen et al. 1989 Finland	Enhanced exercise	outpatient training 60min/week 3 months	n 32 average age 12 yr per cent female 44	control group R	Physical fitness improved HbA1 increased

Wysocki et al. 1989 USA	Self-monitoring of blood glucose	outpatient visits 2–4 weekly 16 weeks' "contract"	n 30 average age 14 yr per cent female 43	control group	Adherence to SMBG increased
Lorini et al. 1990 Italy	Dietary education in groups	outpatient meetings weekly/one month biweekly/ two months	n 36 average age 14 yr per cent female 53	single group	Improved nutrition
Nurick et Johnson 1991 USA	Enhance blood glucose awareness	6 inpatients 8 outpatient 9 inpatients	n 14 age 15 yr age 22 yr age 14 yr	control group	Blood glucose awareness increased
Simell et al. 1991 and 1995 Finland	Diabetes education at the onset of diabetes and adjustment	a week Vs 4 weeks at hospital	n 61 age 0–15 yr (group11–14yr) per cent female 36	control group	No difference in HbA1c or coping
Smith et al. 1991 USA	Enhance coping strategies	summer camp 7 days	n 108 average age 15 yr per cent female 56	single group	Awareness of stress and coping increased
Snyder et al. 1992 USA	Self-monitoring of blood glucose	outpatient 3 months follow up	n 11 average age 15yr per cent female 64	single group	HbA1= Adherence and accuracy improved
Bougneres et al. 1993 France	Transfer from two injections to three	outpatient clinic 1 yr. follow up	n 205 age 10-18 yr per cent female 49	control group R	HbA1 decreased

The DCCT 1994 USA	Enhanced education with intensified insulin treatment	outpatient 4–9 years average=7,4yr	n 125 n 75 average age 15yr per cent female 44–61	control group R	HbA1 decreased Hypos increased; Microangio- pathy decreased
Pichert et al. 1994 a USA	Enchancing diet adjustment	camp 2 weeks 50 min session twice PBL (videotape)	n 16 age 14–15 yr per cent female 50	control group	Dietary adherence increased
Pichert et al. 1994 b USA	Nutrition education traditional Vs problem solving	diabetes camp three small group sessions	n 69 age 10–15yr	control group R	Knowledge skills behaviour improved
Ryden et al. 1994 Sweden	Family therapy in poor control	outpatient 7 sessions 30–60 min 6 months	n 37 average age 13 yr per cent female 59	control group R	HbA1 decreased, Behavioural symptoms decreased
Marrero et al. 1995 USA	Telecommunication technology in counselling	outpatient self-moni- toring data was trans- mitted by modem 2 weekly/1 year	n 106 average age 13 yr per cent female 50	control group R	Nursing time decreased
Schlundt et al. 1996 USA	Group problem solving	camp 2 sessions 50 min	n 48 age 12–15 yr per cent female 52	single group	Dietary self- efficacy improved
Mendez et Belendez 1997 Spain	Behavioural interven- tion to increase treat- ment adherence and stress management	outpatient 12 sessions	n 18 average age 13 yr	control group R	Treatment adherence and stress manage- ment increased
Grey et al. 1998 U.S.A	Coping skills Problem-solving	outpatient group sessions	n 64 age 15.8 yr per cent female 57	control group R	HbA1c improved Stress of diabetes reduced

Topics of study in PBL sessions

1. Insulin

One morning aboard a train approaching Paris on your inter-rail trip you realise that your pouch of supplies for diabetes care has dropped from your bag and been stepped on by a fellow passenger in the corridor. All your insulin pens and insulin ampules are broken. All this happened just before you had been getting ready for breakfast and your injection of insulin.

Things to be learned:

What is the effect of insulin. Development of ketoacidosis. Insulin preparations, their strength and duration. How to obtain insulin. How to pack insulin for a trip.

Things to be discussed:

Have any members of the group been in a situation like this; insulin is missing.
Is it possible to skip the injection?
What are the consequences of skipping an insulin injection?
When at the latest must the insulin be injected?
How to obtain insulin abroad or at home?
How to equip for a journey?

2. Diet

Group members make a recall of one day's regular diet and calculate the carbohydrate content of each meal. A booklet of carbohydrate contents of various foods is available. Portions and quality of carbohydrates are compared with corresponding insulin doses and blood glucose values. Fat and protein content of different meals are also dealt with.

Things to be learned:

Evaluation and division of carbohydrates into meals. Quality of fat. Significance of protein in diet.

3. Diet

A snack served in the session is used as a practise meal. The group members choose their snacks, calculating the carbohydrates they contain.

Several problems are presented with discussions following:

1. You are going to participate in your class mate's birthday party at seven o' clock in the evening. The girls in your class have made pizza and sandwiches and there is plenty to eat and drink.

2. Your class takes a cruise to Stockholm. The departure is at 6:00 p.m. and the return at the same time next day. On board you will go to a disco and stay up until late.
3. You are on a language course in England. After a class your group decides to go to a nearby cafe to eat ice cream. However, it is your dinner-time. Do you join the group?
4. You are going cycling in countryside for the whole day with your friend.

Things to be learned:

How to change the meal and injection plan. Estimation of alcohol in drinks. Effects of alcohol in diabetes. Safe use of alcohol; amount, insulin injections and meals. Dangers of smoking.

Things to be discussed:

How to adjust meals and injections to changes in daily program. How to compensate meals with snacks. Use of sweeteners. Consumption of alcohol, smoking.

4. Blood glucose self-monitoring and goals of treatment

Problems:

1. There are blood sugar values ranging between 4–15 mmol/l in Mikko's log book. The measures are random 1–2 times per week. Mikko's HbA1c is 9.7% (4–6.4%).
2. Maija has done self-monitoring of blood glucose about eight times per week before meals. Blood sugar is usually 4–7 mmol/l before meals, but higher in the morning, 8–12 mmol/l.
3. On Fridays Pekka goes to a disco. On Saturday mornings he often has hypoglycaemic symptoms and once had a hypoglycaemic coma, and was brought to the health centre. He uses self-monitoring of blood glucose infrequently, only 4–6 six measures monthly. Blood sugar before meals is usually 6–8 mmol/l. Pekka's HbA1c is 8.1%. He is going to get a driving licence and has registered with a driving school.
4. Erkki's hobby is football. Practices are nearly every day at 5:00–7:00 p.m. Because his blood sugar values are usually 4–6 mmol/l before going to bed he has increased his night snack with the result that he has gained weight. Nevertheless, the next morning's blood sugar has tended to be 2–3 mmol/l and there have also been symptoms of low blood sugar.
5. Kati's log book shows 8–10 blood glucose values weekly. Values range 4–9 mmol/l. Kati has also calculated the mean of them, which is 6.4 mmol/l. However, her HbA1c-value is 10.2%.

Things to be learned:

Self-monitoring of blood glucose, and its goals. HbA1c, what does it mean, goals for it. How to adjust self-treatment according to blood sugar values. How to take care of and check the blood glucose meter?

Thing to be discussed:

How often and when should blood sugar be measured. What does HbA1c mean? What are the goals in blood glucose self-monitoring or HbA1c?
Why is blood sugar high in the morning?
Why is Pekka's blood sugar low on Saturday mornings? Alcohol consumption? Exercise? How to prevent hypoglycaemic coma? Is it possible for Pekka to get a driving licence?

Why is Kati's HbA1c high in spite of seemingly normal blood sugar values in the log book. Is there something wrong with the machine. Has Kati cheated?

5. Exercise

Problems:

1. Your exercise session is twice a week. On Tuesdays the class is at10:00–11:00 before lunch and on Fridays at 14:00–15:00 p.m.
2. The Biology Club is going to go for a night hike to the Natural Park in order to get acquainted with owl species. You will participate in the excursion, which will start from the boundary of the Park at 7:00 p.m. and end the next morning, when bus transport has been arranged to the town.
3. Your glucose balance has worsened and you think of starting to exercise to improve it.
4. You have gained weight and want to lose 3 kg.
5. You are going to visit your cousin to Lapland; you are planning to ski there for the whole week.

Things to be learned:

What is the effect of exercise on diabetes. Dangers of hypoglycaemia. Adjustment of insulin to different exercise situations. How to lose weight through exercise.

Things to be discussed:

Do you have hypoglycaemic symptoms during or after exercise classes at school? Why? How to prevent and treat the symptoms?
How to prepare to stay up the whole night, insulin injections? Meals? How to manage diabetes the next morning? When should you be going to bed?
What kind of exercise affects weight. How to adjust insulin when losing weight.
How does a diabetic prepare for heavy exercise of long duration?

6. Clinical checks and long-term complications

Problem:

Pekka is a 19-year-old man from Tampere, who started his studies at a travel institute in Porvoo, where he now lives. He has had diabetes since he was two years old. He was attending a diabetes clinic at Tampere University Hospital until he finished college, when his care was transferred to the local health centre. Because of studies he had no time for control visits to the health centre for a year. The insulin prescription was renewed on the telephone at a pharmacy. Pekka takes insulin in a multiple injections schedule but sometimes neglects his shots. According to the summary of his diabetes from the hospital, he has incipient changes in his eye fundus and once his urine microalbumin appeared positive. However, Pekka considers himself very healthy and exercises by playing badmington 2–3 times weekly.

Things to be learned:

Importance of clinic checks. Long-term changes in diabetes. How to find the right clinic for treatment.

Things to be discussed:

Pekka has many problems. Can one neglect control visits? What do changes in the fundus of the eye and urine microalbumin mean? How should Pekka arrange clinic visits to check on his diabetes? What items are checked at clinic visits?

7. Hypoglycaemia

Problem:

Matti is a 21-year-old physical therapist studying in Helsinki. He has had diabetes from the age of three. His insulin doses are Actrapid 12 units three times per day and Protaphan 18 units and Actrapid 4 units in the evening. Matti spent his week-end at his parents' house. On Sunday morning, when eating breakfast he suddenly collapsed and had seizures.

Things to be discussed:

What happened to Matti? Can you image what the parents did? Have you given advice for a case of hypoglycemic coma? What kind of advice? Could it be possible for Matti to avoid hypoglycemic coma?

Things to be learned:

What happens in hypoglycaemic coma? First aid? Reasons of hypoglycaemic coma. (On Saturday Matti had participated in a cycling event of 40 kilometres). Alcohol as a reason for hypoglycaemia. How to avoid hypoglycaemia. Use of diabetes sign.

8. Sick days

Problem

Kalle is a 18-year-old student, who lives in student housing in Tampere. He had had a sore throat and aching limbs for a few days. Yesterday he developed a high fever, nearly 40 degrees Celcius, and a severe cough. Kalle also had stomach pains and was vomiting.

Things to be discussed:

What kind of disease do the symptoms suggest? What about the pains in the stomach?

Things to be learned:

Checking of blood glucose and ketone bodies during illnes. Dosing of insulin, extra doses. What to eat when one feels like vomiting. Symptoms and signs of ketoacidosis. When to go to an emergency unit or first aid station?

9. Social security

Social worker visits in the group to discuss social security concerning young diabetic people.

10. Treatment motivation

Problem:

Antti is a 21-year-old student at the Institute of Technology, who has had diabetes from the age of four. He has taken insulin in a multiple injection system and his glucose control had been good. HbA1c has ranged 7.5–8%. He has done home tests 6–8 times weekly, usually in the morning and before dinner. For nearly a year Antti had a girl friend, who studied at the School of Commercial Studies for the last year. A couple of months ago the girl gave up; telling Antti that she had found a new boy friend. Antti felt depressed and lonely. He had neglected home tests and in general was too tired to exercise and had a feeling of high blood glucose.

Things to be discussed:

How to continue? What ways of helping oneself can one find?

Things to be learned:

Communal psychic services. Support of friends, sisters, brothers and parents is worth remembering. Exercise may also help.

Dear Peter

At the University of Tampere we are conducting a study of diabetes in adolescents.

The purpose is to survey factors influencing the treatment of diabetes, and the goal of the study is to develop treatment.

All diabetic adolescents who are at the phase of transferring from paediatric care to the adult clinic are included in the study.

Please find enclosed questionnaires which we ask you to fill in. Most of the questions can be answered by circling or ticking off one of the alternatives.

There are no right or wrong answers; you should choose the alternative that best fits your situation.

Our objective is to get a realistic picture of your treatment of diabetes and your attitude towards it.

The answers will be dealt with confidentially and will be known only to the doctor in charge of the study. The results will be published in compiled form and thus no individuals' answers can be traced in the published data.

I will be glad to answer any questions concerning the study and give advice in filling in the questionnaires if needed.

Thank for your trouble.

Participant's signature

Questionnaire H

At the beginning there are questions regarding your background, your treatment of diabetes and your attitude towards it

1. Gender a. [_] male b. [_] female

2. Your age

3. Are you
   a. [_] at comprehensive school
   b. [_] at post-comprehensive school
   c. [_] keeping a year off studying
   d. [_] at work
   e. [_] unemployed

4. If you are at comprehensive school, in which grade
   Name of your school

5. If you are doing post-comprehensive education, are you
    a. [_] at upper secondary school
    b. [_] at vocational school
    c. [_] at higher vocational school
    d. [_] at university
    e. [_] on a vocational training course
    f. [_] other education

    The name of your educational institution

6. If you are at work, what is your educational background?
    a. [_] comprehensive school
    b. [_] upper secondary school
    c. [_] vocational school
    d. [_] vocational training course
    e. [_] upper secondary vocational school
    f. [_] university
    g. [_] apprenticeship training

7. If you are at work, what are your tasks

8. You have had diabetes since

9. Mark your insulin doses in the following table
    a. [_] 1. injection o'clock name dose
    b. [_] 2. " " "
    c. [_] 3. " " "
    d. [_] 4. " " "
    e. [_] 5. " " "
    f. [_] Your insulin doses are mixtures of 2 different insulins.

    Write down your insulin doses

10. Do you neglect an injection?
    a. [_] I do not neglect an injection
    b. [_] sometimes
    c. [_] 1–2 times per week
    d. [_] 3-4 times per week
    e. [_] more often

11. Self-monitoring of blood glucose. How many times per week do you measure blood glucose?
    a. [_] 10–20 measures per week
    b. [_] 4–10 " "
    c. [_] 1–2 " "
    d. [_] few random measures
    e. [_] no measures

12. Results of self-monitoring; generally your blood glucose values are:
    a. [_] 4–7 mmol/l
    b. [_] 8–10 "
    c. [_] 11–13 "
    d. [_] greater than 13 mmol/l

13. Urine tests at home; if you do these tests, mark down how many tests per week
    a. [_] regularly, at least 7 times per week
    b. [_] few random tests per week
    c. [_] no urine tests

14. Results of urine tests
    a. [_] most are sugar-free
    b. [_] half of the tests show sugar and half are sugarfree
    c. [_] most of the tests show sugar

15. Estimate your diabetes control, is it
    a. [_] good
    b. [_] satisfactory
    c. [_] poor
    d. [_] I do not know

16. Your exercise (walking, jogging or some other exercise, at leat 30 min at a time)
    a. [_] daily
    b. [_] every other day
    c. [_] 1–2 days per week
    d. [_] no exercise

17. How do you keep to your diet
    a. [_] regularly
    b. [_] fairly regularly
    c. [_] only temporarily
    d. [_] do not follow my diet

18. Do you smoke?
    a. [_] yes, cigarettes per day
    b. [_] no

19. Your alcohol intake?
    a. [_] not at all
    b. [_] more infrequently than once a month
    c. [_] about once a month
    d. [_] twice a month
    e. [_] once a week
    f. [_] several times a week

What kind of alcohol?

1. [_] beer
2. [_] wine
3. [_] spirits

20. Do your family participate in your treatment of diabetes?

	daily times	several times per week	some-	never
	1.	2.	3.	4.
a. [_] in injections	[_]	[_]	[_]	[_]
b. [_] in home tests	[_]	[_]	[_]	[_]
c. [_] in portioning of meals[	_]	[_]	[_]	[_]
d. [_] in estimation of results	[_]	[_]	[_]	[_]
e. [_] in changing of insulin doses	[_]	[_]	[_]	[_]
f. [_] in clinic visits	1.	[_]	every time	
	2.	[_]	infrequently	
	3.	[_]	not at all	

21. What is the order of importance of different factors in diabetes self-care, give a numerical order to the following items:

    a. [_] exercise
    b. [_] home tests
    c. [_] insulin injections
    d. [_] diet
    e. [_] clinic visits

22. What are your goals in diabetes care? Mark a numerical order

    a. [_] to live like peers
    b. [_] good diabetes control
    c. [_] regular daily program
    d. [_] fitness
    e. [_] not needing hospital care
    f. [_] no long-term complications
    g. [_] feel fine

23. We ask you to estimate how much you yourself can influence the course of your diabetes (number 10 means that you yourself can totally determine the course of your diabetes, 0 means that you cannot control it at all)

I cannot control the course of my diabetes	0	1	2	3	4	5	6	7	8	9	10	I can totally control the course of my diabetes

24. How do you think diabetes will influence your health in the future, will it
    a. [_] improve
    b. [_] remain the same
    c. [_] worsen

25. Your plans after school:
    a. [_] continue studies
    b. [_] go to work
    c. [_] do not know

Kindly answer the following questions:

What should you do? Tick off all right alternatives

1. You awaken feeling bad and thirsty. Then you remember that you forgot your insulin shot the night before. Check reveals blood sugar 28 mmol/l. There are ketones in your urine.
   a. You will inject the regular morning dose of insulin, eat and go jogging
   b. You will add short-acting insulin to your morning dose
   c. You will add the same dose of long-acting insulin that you forgot the night before to your morning dose
   d. You will add 1/3 of the amount of insulin that you forgot the night before
   e. You will not inject at all and decide to go to the health centre
   f. You call the nurse and ask for advice
   g. You will inject your ordinary insulin dose and check blood sugar in the afternoon

2. You come home and find only one egg, a small orange and three potatoes along with half a litre of milk in the refrigerator. In a cupboard you find rye crisp.

   There should be 60 g carbohydrates in your dinner. What will you eat?

3. You will have an athletic class at school after lunch and it is supposed to include a ski trip of eight kilometres in a nearby forest.
   a. You will eat your ordinary meal at lunch
   b. As a precaution you will eat more than usual
   c. You will inject more short-acting insulin and eat your ordinary meal
   d. You will decrease your short-acting insulin dose and eat your ordinary meal

4. You easily get hypoglycaemic symptoms during athletic classes. You will take some food for hypoglycaemic feelings. It is
   a. Candies
   b. Rye crisps
   c. An apple
   d. Juice sweetened with sugar
   e. Cheese sandwiches
   f. Artificially sweetened juice

5. You have a stomach problem, vomiting and diarrhoea. You cannot eat anything. You also have fever.
   a. You will inject your ordinary insulin dose and check blood sugar and ketones after two hours
   b. Will reduce your insulin dose by one third.
   c. You decide to go to the health centre
   d. You do not inject because you have not eaten anything

6. If a diabetic consumes alcohol
   a. He/she should follow the meal plan or eat more
   b. The meal should be reduced because of the energy in alcohol

7. The action of long-acting insulin (Monotard, Protaphan, Insulatard, Pitkä, Humutard, Isuhuman-basal) lasts:
   a. 10–12 hours
   b. 20–24 hours
   c. 36 hours

8. Select the sweeteners with a high energy content:
   a. Ordinary sugar
   b. Cyclamate
   c. Saccharin
   d. Fruit sugar
   e. Aspartame

9. Injection of insulin, select the right answers
   a. Insulin absorbs most rapidly from the buttock
   b. Insulin absorbs most rapidly from the stomach
   c. Insulin absorbs most rapidly from the femur
   d. Short-acting insulin should be injected into the stomach
   e. Short-acting insulin should be injected into the buttock and long-acting into the stomach

10. Blood sugar control is good if blood sugar before meals is:
   a. 2–4 mmol/
   b. 7–9 mmol/l
   c. 4–7 mmol/l

Kindly answer the following questions on diabetes treatment

1. You have decided to go to Stocholm by ship. The departure was 6:00 p.m. You planned to eat dinner on board, where the restaurant was opened at 7:00 p.m. When injecting short-acting insulin for dinner, you realise that you had accidentally left the long-acting insulin for the night at home. Your insulin doses are Actrapid 6–8 units x3 and Protaphan 32 unit for the night. How do you manage?

2. There should be 70 gr carbohydrates in your dinner. What will you eat from the buffet.

3. What are the goals of blood sugar control?

   Blood sugar values before meals

   HbA1c in control checks

4. What do you eat for hypoglycaemic symptoms (type of food and amount)

5. In the evening you have a high fever of 39.5 degrees accompanied by vomiting and diarrhoea. What will you do?

6. You and your friends have decided to go to Lapland for skiing. You are going to live in a cottage located far away from the main road and without a telephone. Should you equip especially for your diabetes and how?

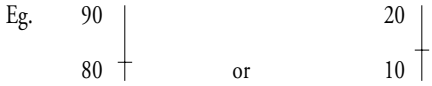
Markku Ojanen
University of Tampere
Department of Psychology

20 Personality traits

You have in front of you a personality test which was composed in a different manner. This test operates on the assumption that you yourself know best what sort of a person you are. It has therefore been composed in such a way that you can report the picture of yourself that you think is right. When you respond you know exactly where you belong as regards each trait. Each trait is described clearly first. There is nothing mysterious about this test; it depends on a shared understanding between the person giving it and the person responding to it.

Each trait is set out so that there are 11 descriptions next to a vertical line. They describe different degrees of the trait in question. The extremes of the line are 100 and 0 points respectively. These numbers are purely technical. The aim is to provide the person responding with sufficient alternatives. The model is the same for each trait. The extremes of the trait as 100 and 0. They describe some trait in a very pure form. The number 50 is where the midpoint of the trait is situated, where it is in balance. Neither extremity carries more weight than the other.

The description is intended to be continuous. You can always draw the line across at any point on the vertical line. Please do so when you think it is wise.



Thus if the description near the number fits you perfectly, draw the line across at that point, but if, for example, the description at 10 is slightly better than that at 20, draw your line across suitably close to 10.

Proceed as follows: read through all 11 descriptions and return to those descriptions which are closest for you. Draw a short line across either at the point where the description describes you extremely well or then between two descriptions which describe you almost equally well. Draw the line closer to one description than the other if its is the more appropriate of the two. – Go through all the traits in the same way.

Describe yourself as you generally are. In your mind create an average of yourself in different situations and circumstances. Make your assessment over a sufficiently long period of time. Think backwards from this day, perhaps for a year and so form an overall picture.

Date

Sex 1 Woman 2 Man

Age in years

1. Feeling of Anxiety

Below this refers to the following, including feeling nervous, tense and agitated. From top to bottom severe anxiety gradually becomes less severe so that by the end there is no feeling at all of anxiety.

Extremely anxious	100	I constantly feel anxious and tense. I feel all strung up.
Very anxious	90	Nervousness and agitation are typical for me. I very seldom feel relaxed. My nerves are tense and it is as if I were being pulled in all directions at once.
Anxious	80	I cannot get away from anxiety, fears and feelings of tenseness. It is hard for me to relax, but not impossible.
Fairly anxious	70	I have a tendency to states of anxiety occurring fairly often. Although the anxiety is not constant it does colour my life
	60	I am familiar with anxiety and agitation, although there are times when it does not trouble me. However, I am more used to having it than not having it.
Slightly anxious	50	Variations in anxiety, some sort of balancing are part of my life. Sometimes I feel anxiety, sometimes I overcome it. Both states are part of me.
Very slightly anxious	40	Although I suffer from anxiety, it is not constant. There are rather more times when it is absent than when it is present.
	30	It is not typical of me to feel anxiety, although I may sometimes get agitated and feel it. It does not last long before it passes.
Hardly anxious at all	20	I don't get anxious about anything. I have enough experience to know what it is, but I do not usually get agitated or feel anxiety.
	10	It is hard to recall feeling anxiety or agitation. I hardly ever feel anxious.
Not anxious at all	0	I only know the word as I have very little experience of it. 1 can only imagine what it is like.

2. Dominance

To what extent do you take the initiative, involve yourself in things or if necessary take the lead? Do you take the lead in any situation at all or do you let others do it and content yourself with following?

Extremely dominant	100	I have no hesitation in taking the lead if at all possible. I am not easily led or directed. I could be called dominant in both positive and negative senses
Very dominant	90	I have a strong tendency to dominate other people. I do not like to give in and I need no encouragement to do things involving leading or directing others.
Dominant	80	Tasks involving leading and directing suit me well and I like to take the lead. I typically involve myself easily in things and express my opinion.
	70	Perhaps I cannot be called 'dominant', but I like to take the lead and be the driving force. Taking the initiative is typical of me.
Fairly dominant	60	I am more prone to dominance than deference, although the two are almost equally balanced: I do not easily take it upon myself to lead the team.
Reasonably dominant	50	I do not see myself as dominant or deferent. Neither of these really suits me. Sometimes I take the initiative, sometimes I follow the others.
	40	I am not deferent in the true sense of the word, but I easily give in and do what the others want. If the situation clearly so requires 1 can take the lead.
Fairly deferent	30	Directing and ordering other people is fairly alien to me, although not entirely unknown or impossible. I am generally content to fall in with what the others want.
Deferent	20	It is natural and easy for me to fall in with what others want. Sometimes I 'rebel', but this feels contrary to my nature and I am content to defer.
Very deferent	10	I am a follower-type; I generally do what the others say. I do not take the initiative unless there is something very unusual.
Extremely deferent	0	Falling in with others is a part of my personality. It is typical of me to defer in almost all cases where there are other people.

Questionnaire M

The questionnaire contains groups of statements. Please read the entire group of statements in each category, then pick out the one statement in that group which best describes the way you feel today.

A	3	I am so sad or unhappy that I can't stand it.
	2	I am blue or sad all the time and can't snap out of it
	1	I feel sad or blue
	0	I do not feel sad
B.	3	I feel that the future is hopeless and that things cannot improve
	2	I feel I have nothing to look forward to
	1	I feel discouraged about the future
	0	I am not particularly pessimistic or discouraged about the future
C.	3	I feel I am a complete failure as a person
	2	As I look back on my life, all I can see is a lot of failures
	1	I feel I have failed more than the average person
	0	I do not feel like a failure
D.	3	I am dissatisfied with everything
	2	I don't get satisfaction out of anything any more
	1	I don't enjoy things the way I used to
	0	I am not particularly dissatisfied
E.	3	I feel as though I am very bad or worthless
	2	I feel quite guilty
	1	I feel bad or unworthy a good part of the time
	0	I don't feel particularly guilty
F.	3	I hate myself
	2	I am disgusted with myself
	1	I am disappointed in myself
	0	I don't feel disappointed in myself
G.	3	I would kill myself if I had the chance
	2	I have definite plans about committing suicide
	1	I feel I would be better off dead
	0	I don't have any thought of harming myself
H.	3	I have lost all my interest in other people and don't care about them at all
	2	I have lost most of my interest in other people and have little feeling for them
	1	I am less interested in other people than I used to be
	0	I have not lost interest in other people

I.	3	I can't make any decisions at all any more
	2	I have great difficulty in making decisions
	1	I try to put off making decisions
	0	I make decisions about as well as ever
J.	3	I feel that I am ugly or repulsive looking
	2	I feel that there are permanent changes in my appearance and they make me look unattractive
	1	I am worried that I am looking old or unattractive
	0	I don't feel that I look any worse than I used to
K.	3	I can't do any work at all
	2	I have to push myself very hard to do anything
	1	It takes extra effort to get started at doing something
	0	I can work about as well as before
L.	3	I get too tired to do anything
	2	I get tired from doing anything
	1	I get tired more easily than I used to
	0	I don't get any more tired than usual
M.	3	I have no appetite at all any more
	2	My appetite is much worse now
	1	My appetite is not as good as it used to be
	0	My appetite is no worse than usual

Questionnaire C

The following questions survey your attitudes. Choose by ticking the alternative which corresponds to your attitude:

Alternatives
1. Very satisfied
2. Moderately satisfied
3. Neither
4. Moderately dissatisfied
5. Very dissatisfied

		1	2	3	4	5
1A	How satisfied are you with the amount of time it takes to manage your diabetes?	[_]	[_]	[_]	[_]	[_]
2A	How satisfied are you with the amount of time you spend getting check ups?	[_]	[_]	[_]	[_]	[_]
3A	How satisfied are you with the time it takes to determine your sugar level?	[_]	[_]	[_]	[_]	[_]
4A	How satisfied are you with your current treatment?	[_]	[_]	[_]	[_]	[_]
5A	How satisfied are you with the flexibility you have in your diet ?	[_]	[_]	[_]	[_]	[_]
6A	How satisfied are you with the burden your diabetes is placing on your family?	[_]	[_]	[_]	[_]	[_]
7A	How satisfied are you with your knowledge about your diabetes	[_]	[_]	[_]	[_]	[_]
8A	How satisfied are you with your sleep?	[_]	[_]	[_]	[_]	[_]
9A	How satisfied are you with your social relationships and friendships?	[_]	[_]	[_]	[_]	[_]
10A	How satisfied are you with your school or work?	[_]	[_]	[_]	[_]	[_]
11A	How satisfied are you with the appearance of your body?	[_]	[_]	[_]	[_]	[_]
12A	How satisfied are you with the time you spend exercising?	[_]	[_]	[_]	[_]	[_]
13A	How satisfied are you with your leisure time?	[_]	[_]	[_]	[_]	[_]
14A	How satisfied are you with life in general?	[_]	[_]	[_]	[_]	[_]

15A	How satisfied are you with your performance in school?	[_]	[_]	[_]	[_]	[_]
16A	How satisfied are you with how your class mates treat you?	[_]	[_]	[_]	[_]	[_]
17A	How satisfied are you with your attendance in school?	[_]	[_]	[_]	[_]	[_]

18A Compared to other persons your age, would you say your health is:

- Excellent [_]
- Good [_]
- Satisfactory [_]
- Poor [_]
- Very poor [_]

Alternatives for the following questions:

1. Never
2. Very seldom
3. Sometimes
4. Often
5. All the time

		1	2	3	4	5
1B	How often do you feel pain associated with the treatment of your diabetes?	[_]	[_]	[_]	[_]	[_]
2B	How often are you embarrassed by having to deal with your diabetes in public?	[_]	[_]	[_]	[_]	[_]
3B	How often do you have low blood sugar?	[_]	[_]	[_]	[_]	[_]
4B	How often do you feel physically ill?	[_]	[_]	[_]	[_]	[_]
5B	How often does your diabetes interfere with your family life?	[_]	[_]	[_]	[_]	[_]
6B	How often do you have a bad nights sleep?	[_]	[_]	[_]	[_]	[_]
7B	How often do you find your diabetes limiting your social relationships and friendships?	[_]	[_]	[_]	[_]	[_]
8B	How often do you feel good about yourself?	[_]	[_]	[_]	[_]	[_]
9B	How often do you feel restricted by your diet?	[_]	[_]	[_]	[_]	[_]
10B	How often does your diabetes keep you from driving a car or using a machine (for example, a typewriter)?	[_]	[_]	[_]	[_]	[_]
11B	How often does your diabetes interfere with you exercising?	[_]	[_]	[_]	[_]	[_]
12B	How often do you miss work, school or household duties because of your diabetes?	[_]	[_]	[_]	[_]	[_]

13B	How often do you find yourself explaining what it means to have diabetes?	[_]	[_]	[_]	[_]	[_]
14B	How often do you find that your diabetes interrupts your leisure time activities?	[_]	[_]	[_]	[_]	[_]
15B	How often are you teased because you have diabetes?	[_]	[_]	[_]	[_]	[_]
16B	How often do you feel that because of your diabetes you go to the bathroom more than others?	[_]	[_]	[_]	[_]	[_]
17B	How often do you find you eat something you shouldn't rather than tell someone that you have diabetes?	[_]	[_]	[_]	[_]	[_]
18B	How often do you hide from others the fact that you are having an insulin reaction?	[_]	[_]	[_]	[_]	[_]
19B	How often do you find that your diabetes prevents you participating in school activities (from sports team etc)?	[_]	[_]	[_]	[_]	[_]
20B	How often do you find your diabetes prevents you from going out to eat with your school friends?	[_]	[_]	[_]	[_]	[_]
21B	How often do you feel that your diabetes is limiting your career or what you will be able to do in the future?	[_]	[_]	[_]	[_]	[_]
22B	How often do you find that your parents are too protective of you?	[_]	[_]	[_]	[_]	[_]
23B	How often do you feel that your parents worry too much about your diabetes?	[_]	[_]	[_]	[_]	[_]
24B	How often do find that your parents act as if diabetes is their disease, not yours?	[_]	[_]	[_]	[_]	[_]
1C	How often do you worry about whether you will get married?	[_]	[_]	[_]	[_]	[_]
2C	How often do you worry about whether you will have children?	[_]	[_]	[_]	[_]	[_]
3C	How often do you worry whether you will not get job you want?	[_]	[_]	[_]	[_]	[_]
4C	How often do you worry about whether you will pass out?	[_]	[_]	[_]	[_]	[_]
5C	How often do you worry about whether you will be able to complete your education?	[_]	[_]	[_]	[_]	[_]
6C	How often do you worry that your body looks different because you have diabetes?	[_]	[_]	[_]	[_]	[_]

7C	How often do you worry that you will get complications from your diabetes?	[_]	[_]	[_]	[_]	[_]
8C	How often do you worry about whether someone will not go out with you because you have diabetes?	[_]	[_]	[_]	[_]	[_]
9C	How often do you worry that your teachers treat you differently because of your diabetes?	[_]	[_]	[_]	[_]	[_]
10C	How often do you worry that your diabetes will disrupt something you are currently doing in school (for example, act in a play, continue on sports etc)?	[_]	[_]	[_]	[_]	[_]
11C	How often do you worry that because of your diabetes you are behind in terms of dating, going to parties, and keeping up with your friends?	[_]	[_]	[_]	[_]	[_]
12C	How often do you meet distrust and rejection when your diabetes comes out?	[_]	[_]	[_]	[_]	[_]

APPENDIX 9.

Please, answer the following questions according to how much you agree with the statements. Consider each statement carefully.

1 = agree totally
2 = agree somewhat
3 = do not know
4 = do not agree
5 = totally disagree

1.	Avoiding diabetes complications is a matter of luck	1	2	3	4	5
2.	Blood sugars will be what they will be	1	2	3	4	5
3.	Blood sugars are controlled by chance	1	2	3	4	5
4.	When my sugar is high it's because of something I've done	1	2	3	4	5
5.	When my diabetes is under control, it is because other people have taken care of me	1	2	3	4	5
6.	Whatever I do, my diabetes will be out of control	1	2	3	4	5
7.	It is a question of chance if my diabetes control is good or poor	1	2	3	4	5
8.	Regular doctor's visits avoid problems	1	2	3	4	5
9.	Avoiding complications will be the care of other people	1	2	3	4	5
10.	Regular communication with other people with diabetes is the best way to avoid complications	1	2	3	4	5
11.	When my diabetes is out of control, it is by accident	1	2	3	4	5
12.	Good control is a matter of luck	1	2	3	4	5
13.	When my blood sugar is high it's because I've made a mistake	1	2	3	4	5
14.	If it's meant to be, my diabetes will be in control	1	2	3	4	5
15.	If I succeed in avoiding complications it is because of something I've done	1	2	3	4	5
16.	With the aid of skilful health care personnel I can keep blood sugars good	1	2	3	4	5
17.	My family is a big help in controlling my diabetes	1	2	3	4	5
18.	I can avoid complications	1	2	3	4	5

19.	What I do is the main influence on my diabetes control	1	2	3	4	5
20.	Complications are the result of carelessness	1	2	3	4	5
21.	I am responsible for my blood sugar control	1	2	3	4	5
22.	My family has an influence on my health	1	2	3	4	5
23.	Other people have a big responsibility for my blood sugar control	1	2	3	4	5
24.	I can only do what my doctor tells me	1	2	3	4	5
25.	I can control my diabetes by treating it correctly	1	2	3	4	5
26.	Whatever I do complications are probably not avoidable	1	2	3	4	5
27.	When my blood sugar is high it's up to me how soon I will be in condition	1	2	3	4	5

Dear Parents

At the University of Tampere we are conducting a study on diabetes in adolescents.

The purpose is to survey factors influencing the treatment of diabetes, and our goal is to develop treatment.

All diabetic adolescents who are at the phase of transferring from paediatric care to the adult clinic are included in the study, as are their parents.

Please find enclosed questionnaires which we ask you to fill in. Most of the questions can be answered by circling or ticking off one of the alternatives.

There are no right or wrong answers; you should choose the alternative that best fits your situation.

Our aim is to get a real picture of the care and attitudes of diabetic adolescents as well as the attitudes of their families towards diabetes.

The answers will be dealt with confidentially and remain known only to the doctor in charge of the study. The results will be published with all answers compiled and thus no individuals'answers will be liable to exposure.

I will be glad to answer any questions concerning the study and give advice in filling the questionnaires if needed.

Thank for your trouble.

Participant's signature

Questionnaire D

1. a. Your son/daughter has no problems of adjustment
   b. He/she has minimal problems of adjustment but no difficult psychological problems and is living a normal life
   c. He/she has some problems of adjustment which have caused minimal psychological problems but is living a normal life
   d. He/she has moderate problems of adjustment to diabetes which have caused recurrent problems in his/her life
   e. He/she has severe problems of adjustment to diabetes and needs a psychiatrist's/psychologist's care

2. Compared to the time when your son's/daughter's diabetes was diagnosed, your son's/daughter's problems of adjustment have
   1. [_] decreased
   2. [_] remained the same
   3. [_] increased
   4. [_] there have been no problems at any time

3. Compared to the time when your son's/daughter's diabetes was diagnosed your own adjustment to your child's disease has
   1. [_] become easier
   2. [_] remained the same
   3. [_] become more difficult
   4. [_] there have been no difficulties at any time

4. Is there insulin-treated diabetes in your family?
   1. [_] in your parents
   2. [_] in your sisters and brothers
   3. [_] in your nephews or nieces
   4. [_] in your other children
   5. [_] in yourself 1. [_] father 2. [_] mother
   6. [_] no one has insulin-treated diabetes

5. Do you participate in the treatment of your son's/daughter's diabetes?

	daily	several times	some-times per week	never
	1.	2.	3.	4.
a. [_] in injections	[_]	[_]	[_]	[_]
b. [_] in home tests	[_]	[_]	[_]	[_]
c. [_] in portioning of meals	[_]	[_]	[_]	[_]
d. [_] in estimation of results	[_]	[_]	[_]	[_]
e. [_] in changing of insulin doses	[_]	[_]	[_]	[_]

   f. [_] in clinic visits
      1. [_] every time
      2. [_] more infrequently
      3. [_] not at all

6. What is the order of importance of different factors in diabetes self care? Please mark down a numerical order
   a. [_] exercise
   b. [_] home tests
   c. [_] insulin injections
   d. [_] diet
   e. [_] clinic visits

7. Which goals do you value in diabetes care? Please mark down a numerical order
   a. [_] to live like peers
   b. [_] good diabetes control
   c. [_] regular daily program
   d. [_] good fitness
   e. [_] no need for hospital care
   f. [_] no long-term complications
   g. [_] feel fine

23. We ask you to estimate how much the diabetic self can influence the course of diabetes (number 10 means that he/she can totally determine the course of diabetes, 0 means no control all)

    One cannot control 0 1 2 3 4 5 6 7 8 9 10 One can totally control

9. How do you think diabetes will influence your son's/daughter's health in the future, will it
   a. [_] improve
   b. [_] remain the same
   c. [_] worsen

10. Do you have, or have you had high blood pressure in your family?
    a. [_] in your parents, how many?
    b. [_] in your brothers and sisters, how many?
    c. [_] yourselves, parents, one of you or both?
    d. [_] in your other children, how many?
    e. [_] no one in your family has or has had high blood pressure

11. Profession/ work of father

12. Profession/work of mother

13. Your professional education:

	a. father	b. mother
1.	[_] university education	[_]
2.	[_] institutional education	[_]
3.	[_] vocational education	[_]
4.	[_] vocational short course	[_]
5.	[_] some other education	[_]
6.	[_] without profession	[_]

14. Does your son/daughter master diabetes self-care
    a. [_] surely
    b. [_] fairly surely
    c. [_] rather unsurely
    d. [_] unsurely

15. What are your relations with your diabetic adolescent like?
    a. [_] without problems
    b. [_] there are problems:

Dear Peter

At the University of Tampere we are conducting a study on diabetes in adolescents.

You have been chosen as a control subject representing a healthy adolescent. Please find enclosed questionnaires which we ask you to fill in. Most of the questions can be answered by circling or ticking off one of the alternatives.

There are no right or wrong answers; you should choose the alternative that best fits your situation.

The answers will be dealt with confidentially and will be known only to the doctor in charge of the study. The results will be published in compiled form and no individuals' answers can be traced in the published data.

I shall be glad to answer all questions concerning the study and give advice in filling in the questionnaires if needed.

Thank for your trouble.

Participant's signature

At the beginning there are questions regarding your background.

1. Gender a. [_] male b. [_] female

2. Your age

3. Are you
   a. [_] at comprehensive school
   b. [_] in post-comprehensive school education
   c. [_] keeping a year off studying
   d. [_] at work
   e. [_] unemployed

4. If you are at comprehensive school, in which grade

   Name of your school

5. If you are doing post-comprehensive education, are you
   a. [_] at upper secondary school
   b. [_] at vocational school
   c. [_] at higher vocational school
   d. [_] at university
   e. [_] on a vocational training course
   f. [_] on other education

   The name of your educational institution

6. If you are at work, what is your educational background?
    a. [_] comprehensive school
    b. [_] upper secondary school
    c. [_] vocational school
    d. [_] vocational training course
    e. [_] upper secondary vocational school
    f. [_] university
    g. [_] apprenticeship training

7. If you are at work, what are your tasks

8. Your exercise? (walking, jogging or some other exercise, at least 30 min at a time)
    a. [_] daily
    b. [_] every other day
    c. [_] on 1–2 days per week
    d. [_] no exercise

9. Do you smoke ?
    a. [_] yes, _____cigarettes per day
    b. [_] no

10. Your alcohol intake?
    a. [_] not at all
    b. [_] more infrequently than once a month
    c. [_] about once a month
    d. [_] twice a month
    e. [_] once a week
    f. [_] several times a week

    Which alcohol?
    1. [_] beer
    2. [_] wine
    3. [_] spirits

11. Your plans after school:
    a. [_] continue studies
    b. [_] go to work
    c. [_] do not know

Questionnaire C

The following questions survey your attitudes. Choose by ticking off the alternative which corresponds your attitude:

Alternatives
1. Very satisfied
2. Moderately satisfied
3. Neither
4. Moderately dissatisfied
5. Very dissatisfied

		1	2	3	4	5
8A	How satisfied are you with your sleep?	[_]	[_]	[_]	[_]	[_]
9A	How satisfied are you with your social relationships and friendships?	[_]	[_]	[_]	[_]	[_]
10A	How satisfied are you with your school or work?	[_]	[_]	[_]	[_]	[_]
11A	How satisfied are you with the appearance of your body?	[_]	[_]	[_]	[_]	[_]
12A	How satisfied are you with the time you spend exercising?	[_]	[_]	[_]	[_]	[_]
13A	How satisfied are you with your leisure time?	[_]	[_]	[_]	[_]	[_]
14A	How satisfied are you with life in general?	[_]	[_]	[_]	[_]	[_]
15A	How satisfied are you with your performance in school?	[_]	[_]	[_]	[_]	[_]
16A	How satisfied are you with how your class mates treat you?	[_]	[_]	[_]	[_]	[_]
17A	How satisfied are you with your attendance in school?	[_]	[_]	[_]	[_]	[_]

18A Compared to other persons of your age, would you say your health is:

Excellent [_]
Good [_]
Satisfactory [_]
Poor [_]
Very poor [_]

APPENDIX 13.

Results of the personality traits test

Personality trait	At transfer		At the end		Group I	Group II	
	PBL group	Controls	PBL group	Controls	Healthy controls		
	mean	**mean**	**mean**	**mean**	**mean**	**mean**	**p**
	SD	SD	SD	SD	SD	SD	
Openness	**62.2**	**69.5**	**60.7**	**64.1**	**65.3**	**68.3**	* 1,2,3
	15.5	15.4	17.7	19.5	16.9	16.9	
Sociability	**69.6**	**69.5**	**69.4**	**69.3**	**65.3**	**68.3**	
	12.4	15.4	14.7	16.3	16.9	16.9	
Anxiety	**31.7**	**31.8**	**34.0**	**38.3**	**35.2**	**35.6**	* 5
	13.0	16.2	15.8	18.6	17.2	16.8	
Self- confidence	**69.1**	**72.0**	**67.5**	**70.2**	**69.5**	**73.6**	* 2, 3
	14.7	14.1	18.3	17.5	16.8	15.1	
Responsibility	**71.4**	**68.7**	**70.8**	**69.4**	**65.5**	**70.1**	* 3
	14.9	16.9	17.0	18.2	14.7	16.3	
Mood	**70.0**	**70.5**	**66.8**	**68.4**	**70.9**	**70.4**	
	12.2	19.0	19.5	18.1	16.4	15.8	
Sensitiveness	**54.4**	**61.9**	**61.2**	**63.4**	**59.2**	**62.0**	
	26.1	25.5	24.1	27.0	23.8	24.7	
Social courage	**69.6**	**70.6**	**69.4**	**69.3**	**69.4**	**71.5**	
	12.4	16.1	14.7	16.3	15.6	15.7	
Dominance	**61.4**	**66.7**	**61.8**	**62.4**	**62.8**	**65.6**	
	12.7	18.4	13.2	15.0	16.1	15.8	
Need of variety	**66.2**	**70.0**	**66.1**	**67.0**	**72.8**	**70.6**	* 3
	17.9	20.2	21.0	17.9	15.9	15.7	
Personal variation	**51.3**	**60.8**	**56.4**	**58.5**	**56.3**	**54.7**	* 1
	20.0	25.8	21.5	21.5	22.9	22.6	
Selfishness	**47.6**	**51.9**	**47.0**	**44.8**	**49.2**	**48.4**	
	19.5	17.4	20.2	15.7	18.5	17.1	
Self-control	**56.1**	**53.6**	**59.6**	**56.5**	**63.1**	**59.1**	* 4
	19.9	21.3	17.8	20.4	21.3	20.6	
Impulsiveness	**56.5**	**64.3**	**56.9**	**63.6**	**65.0**	**63.2**	* 1, 2, 3
	15.4	17.8	18.5	16.5	16.7	14.5	
Activity	**63.1**	**60.8**	**59.6**	**59.6**	**67.1**	**65.2**	
	17.3	20.1	19.1	20.1	17.4	18.1	
Kindness	**73.7**	**77.2**	**74.7**	**78.0**	**74.1**	**75.0**	
	14.9	12.1	14.5	11.1	14.3	14.5	
Creativeness	**62.0**	**61.9**	**65.1**	**63.4**	**61.8**	**65.1**	
	17.2	20.4	17.7	23.3	19.2	17.7	
Flexibility	**62.8**	**64.5**	**64.9**	**69.0**	**68.6**	**67.7**	* 3
	17.4	18.5	17.5	15.3	15.4	15.3	
Persistence	**70.0**	**68.2**	**65.3**	**68.7**	**67.4**	**69.6**	
	14.6	17.2	15.5	19.7	17.4	15.5	
Control of life	**72.9**	**73.6**	**73.6**	**72.7**	**77.6**	**78.2**	
	17.5	17.3	19.4	20.0	16.1	14.9	
Purpose of life	**78.4**	**76.9**	**78.2**	**74.8**	**78.7**	**79.5**	
	17.5	16.0	14.9	23.5	17.5	18.2	

* = $p < 0.05$

p^1 = PBL vs. controls at transfer

p^2 = PBL vs. healthy controls Group I

p^3 = PBL vs. healthy controls Group II

p^4 = Controls vs. healthy controls Group I

p^5 = Controls at transfer vs. at the end

APPENDIX 14.

List of education material used in the current study

1. Guide for treatment of juvenile diabetes, The Finnish Diabetes Association
2. Handbook of carbohydrates in different foods, Novo Care
3. Diabetes and alcohol, The Finnish Diabetes Association
4. Self-care of diabetic foot, The Finnish Diabetes Association
5. Articles from Diabetes and Diablo magazines, The Finnish Diabetes Association