Parental knowledge and metabolic control of children and young adults with type 1 diabetes

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Abstract

Introduction: The authors aimed to answer the following questions: 1) What level of knowledge of type 1 diabetes do the parents of children and young adults with this disease have? 2) Will this level of knowledge increase after 1 year of observation? 3) Does improving the knowledge of young adults and their parents result in better metabolic control of the patients?
Material and methods: This study included 227 patients between the ages of 5 and 20 years with type 1 diabetes. The research was conducted from March 2009 to June 2011. The following two time points were examined: the beginning of the study (test 1a) and one year later (test 1b). The knowledge levels of the patients and parents were obtained using a survey and a knowledge test.
Results: Comparison of the results from the two study time points showed that the respondents had a significantly higher level of knowledge after 1 year (p = 0.001). The comparison of glycated hemoglobin levels between the two time points in patients with type 1 diabetes revealed that the levels were significantly higher at test 1b compared to test 1a (p = 0.0005).
Conclusions: The parents of children and young adults with type 1 diabetes demonstrate a satisfactory level of theoretical knowledge of therapeutic conduct and self-monitoring principles. The test 1b results demonstrated a higher level of theoretical knowledge in all respondents and poorer metabolic control. Poorer metabolic control in some patients suggests that metabolic control in type 1 diabetes depends on factors other than education. Further research is necessary to determine these additional factors.

Key words: children, education of patients, type 1 diabetes mellitus, young adult.

Introduction

Type 1 diabetes is the most common chronic childhood disease. The treatment goal for type 1 diabetes is to achieve good metabolic control by maintaining normal levels of blood glucose, glycated hemoglobin (HbA_{1c}), blood pressure, lipid parameters and body weight, while avoiding hypoglycemia. In treating children, adolescents and young adults with type 1 diabetes, an additional goal is to achieve and maintain proper and

healthy physical development, as well as a normal pubertal course (i.e., age and gender appropriate), while ensuring a good quality of life for the patients and their families [1].

The aim of metabolic control is to maintain HbA_{1c} levels at ≤ 6.5%, with stable blood glucose levels, while minimizing hypoglycemia. This process helps to prevent the occurrence of acute and chronic complications and allows patients to lead normal and active family, work and social lives [1].

Children and adolescents with type 1 diabetes and their caregivers should actively participate in the treatment process. The treatment of type 1 diabetes includes adequate insulin therapy, proper nutrition, physical activity, health education and self-care performed by the patients [1–3].

Diabetes education is a continual, integral and crucial component of the therapeutic treatment of diabetes and also helps to ensure the success of all other therapeutic methods. All patients in the developmental stage who are diagnosed with type 1 diabetes and their parents have the right to comprehensive and professional education that should prepare them to take control of diabetes [1, 4–9].

However, diabetes education should be individualized and realistic [10, 11]. To be effective, diabetes education should be a continuous, repetitive and structured process. A systematic educational program should be subject to external evaluation, and trained educators should ensure the quality of its implementation [12, 13].

Continuous education is usually conducted in an outpatient setting (clinic, local community), but it is also available in hospitals. Education can occur in individual and/or group learning settings and should address the issues of self-monitoring and psychosocial concerns. Continuous educational programs should also include interactive education tools that are available to sick children and adolescent patients [14–18].

Patients and their families should also be taught how to observe, monitor and recognize the symptoms of a lack of metabolic control [19]. Diabetes self-monitoring involves determining the concentrations of glucose and ketone bodies in blood and urine, measuring blood pressure and body weight systematically, observing symptoms of hypoglycemia and hyperglycemia, self-monitoring of foot health, keeping a self-monitoring log book, and undergoing regular check-ups at a diabetes clinic. One of the basic and most important elements of self-monitoring is to self-monitor and record blood glucose levels.

The principles of proper patient education have been integrated in children's diabetes centers for several years [1]. Periodic assessments of the knowledge of parents and caregivers may play a role in determining and addressing knowledge gaps. Moreover, treatment results are greatly influenced by how well these therapeutic programs address the needs of patients and their caregivers. Therefore, it is important to assess the current knowledge of parents of children and young adults with type 1 diabetes and its impact on the degree of metabolic control.

The aim of this work was to answer the following questions.

– What level of knowledge of type 1 diabetes do the parents of children and young adults with this disease have?
– Will this level of knowledge increase after 1 year of observation?
– Does improving the knowledge of young adults and their parents result in better metabolic control of the patients?

Material and methods

In addition to their parents, this study included 227 patients with type 1 diabetes who were under the care of the Department of Pediatric Diabetology and the Diabetes Clinic for Children at the University Clinical Centre in Gdansk. The research was conducted at the following two time points (with the same patients): at the beginning of the study (test 1a) and 1 year later (test 1b).

The results were based on the analysis of the authors' questionnaire, which was completed by the young adults and, in the case of children, by their parents. The questionnaires were collected from March 2009 to June 2011. The study included patients who visited the department or clinic to obtain specialist advice. All respondents agreed to participate in the study.

The survey, which consisted of two parts, was administered to the parents of children up to 18 years of age and to patients over 18 years of age. The first part included questions on basic demographic data, disease duration and date of the last training. The second part tested theoretical knowledge of type 1 diabetes. The test contained 18 test questions, each with one correct answer, concerning the nature of the disease, basic treatment principles and occurrence of metabolic disorders and complications (Table I).

The serum HbA_{1c} levels recorded in the patients' medical records were analyzed as the main criterion of carbohydrate metabolism control in type 1 diabetes. According to the criteria provided by the Polish Diabetes Association, HbA_{1c} levels ≤ 6.5% are regarded as good metabolic control [1]. An HbA_{1c} level of 7.5% was used as the value to divide the respondents into 2 groups, one with average metabolic control and the other with poor control.

Table I. Issues included in the test evaluating the level of knowledge of parents and young adults about type 1 diabetes [20]

Number of the question	Issues included in the test
1	The concept of diabetes
2	The place of insulin synthesis
3, 4, 5, 6, 8	Basic principles of healthy nutrition
7	The definition of a carbohydrate unit
9, 10, 11, 12	The role of exercise in the treatment and the principles of taking it up
13	The knowledge of acute metabolic disorders
14, 15	Self-monitoring
16	The interpretation of the measurement results of glucose concentration in capillary blood
17	Indications for glucagon administration
18	Symptoms of hyperglycemia

Furthermore, selected clinical patient data evaluating the length and nutritional status of each child were analyzed. The nutritional status of the patients was assessed based on the length and weight measurements and the body mass index (BMI) analysis. Growth charts compiled by the Polish National Research Project OLAF were used to analyze the nutritional status of the children [20, 21].

Statistical analysis

Statistica PL 10 was used for the data analysis. The results are presented as the arithmetic mean and median, and the dispersion of the results was assessed with the standard deviation as well as the minimum and maximum values.

Statistical inference was performed depending on the scale type and the distribution of the results using nonparametric methods. To analyze the results of the variables from the nominal scale, tabulation and a χ^2 test were used; Pearson's correlation analysis was used for the variables from the quantitative scale.

To verify the significance of differences between the studies, the McNemar test was used. To compare between-group differences, the Mann-Whitney *U* test (a non-parametric equivalent of Student's *t*-test for unpaired variables) or the Kruskal-Wallis one-way analysis of variance by ranks (non-parametric equivalent for the analysis of variance) was used. To determine statistically significant differences between two or more groups, *post hoc* tests were used for non-parametric analyses, and $p < 0.05$ was considered significant.

Results

At time points 1a and 1b there were 104 (45.8%) and 79 (42.7%) male patients and 123 (54.2%) and 106 (57.3%) female patients, respectively. The study included patients between 5 and 20 years of age, among whom 144 (63.4%) lived in urban areas, and 83 (36.6%) lived in rural areas. The patients had been treated for type 1 diabetes for 3 to 17 years, and the mean disease duration was 6.6 years.

The patients underwent two different methods of insulin therapy. At time points 1a and 1b, the majority of children (174/227 (77%) and 147/185 (79.5%), respectively) were treated with continuous subcutaneous insulin infusion (CSII). The remaining patients (53/227 (23%) and 38/185 (20.5%), respectively) received insulin using an insulin pen. The patient characteristics are shown in Table II.

Knowledge levels were assessed using a test that contained 18 questions concerning the nature of the disease and the basic principles of treatment, metabolic disorders and complications.

Table II. General characteristics of the population in tests 1a and 1b

Parameter	Test 1a			Test 1b		
Gender (M/F)	104/123 (45.8%/54.2%)			79/106 (42.7%/57.3%)		
Place of residence (R/U)	83/144 (36.6%/63.4%)			72/113 (38.9%/61.1%)		
Parameter	**Mean ± SD**	**Median**	**Minimum – maximum**	**Mean ± SD**	**Median**	**Minimum – maximum**
Age [years]	13.5 ±3.4	14	5–19	14.4 ±3.5	15	6–20
Disease duration [years]	6.6 ±3.1	6	3–17			
Elapsed time since last training [years]	4.3 ±3.3	3.25	0.5–17	3.1 ±2.8	2	0.5–15
Treatment method (pen/CSII)	53/174 (23.3%/76.7%)			38/147 (20.5%/79.5%)		

Each question had one correct answer for which the parents and young adults received one point, and the maximum score was 18 points.

A detailed test analysis showed that in tests 1a and 1b, the most difficult questions were 3 and 13. Question 3 related to the basic principles of rational nutrition, and question 13 related to acute metabolic disorders in type 1 diabetes.

After 1 year, there were more correct responses regarding the definition of a bread unit (BU), the principles of healthy nutrition, the indications for glucagon administration, and the symptoms of hyperglycemia, whereas there were fewer correct answers regarding acute metabolic disorders (Table III).

Analysis of the length and weight measurements and BMI values at time points 1a and 1b are shown in Table IV.

The knowledge level, metabolic control (based on HbA_{1c} values), and occurrence of nutritional status disorders were compared between time points 1a and 1b. The results indicated that the respondents had a significantly higher level of knowledge at time point 2 (mean ± SD: 14.1 ±2.6 vs. 14.8 ±2, $p = 0.001$, Figure 1).

The results also showed that the HbA_{1c} levels were significantly higher at time point 1b compared with time point 1a (mean ± SD: 8.7 ±1.9 vs. 8.55 ±1.8, $p = 0.0005$; Figure 2).

The occurrence of nutritional status disorders was compared between time points 1a and 1b. At both time points, the incidence of overweight and obese body status was comparable (Table V).

Discussion

Type 1 diabetes is one of the most common incurable chronic diseases occurring during development.

The aim of diabetes treatment is to achieve metabolic control, reduce the occurrence of diabetic ketoacidosis and severe hypoglycemia, and prevent chronic organ complications [1, 22]. In recent years, there has been a tendency to accept lower HbA_{1c} levels as a criterion of metabolic control in type 1 diabetes. One study conducted at 305 centers in Germany and Austria between 1995 and 2009 showed significant improvement in metabolic control in children and adolescents with type 1 diabetes and a simultaneous decrease in hypoglycemic events. These authors emphasized that this improvement was achieved using modern therapy methods and improved education methods for the patients and their families [23].

According to the latest recommendations of the American Diabetes Association, when treating toddlers and preschoolers (0–6 years old) with type 1 diabetes, the goal should be to achieve and maintain HbA_{1c} levels < 8.5%, compared to < 8.0% for school children (6–12 years) and < 7.5% for adolescents and young adults (13–19 years), while simultaneously preventing episodes of severe hypoglycemia [22].

The 2012 recommendations of the International Society for Pediatric and Adolescent Diabetes

Table III. Assessment of the degree of difficulty of particular questions in the test (based on the number of correct answers given) at time points 1a and 1b

Question no.	Question content	Percent of correct answers in test 1a	Percent of correct answers in test 1b
3	The principles of healthy nutrition	26.4	39.5
7	The definition of BU	90.8	96.2
13	Acute metabolic disorders	22.5	15.7
17	Indications for glucagon administration	94.7	97.3
18	Symptoms of hyperglycemia	92.5	97.3

Table IV. Body weight and height and BMI values in the study population in tests 1a and 1b

Time point of the study	Parameter	Mean ± SD	Median	Minimum – maximum
Test 1a	Body height [cm]	158.9 ±18.4	162.5	91–191
	Body weight [kg]	51.7 ±17	51.6	13–95
	BMI [kg/m²]	19.8 ±3.4	19.7	11.9–32.5
Test 1b	Body height [cm]	161.6 ±17.5	165	91–193
	Body weight [kg]	54.7 ±17.2	56.3	14.4–99.7
	BMI [kg/m²]	20.3 ±3.4	20.1	13.2–33.1

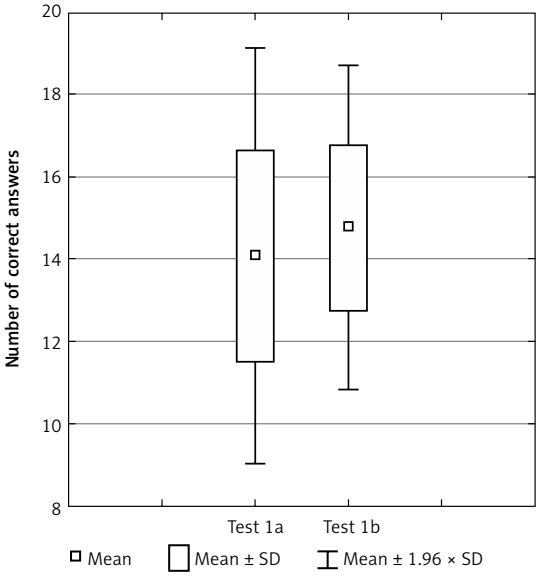

Figure 1. Comparison of the level of knowledge in tests 1a and 1b

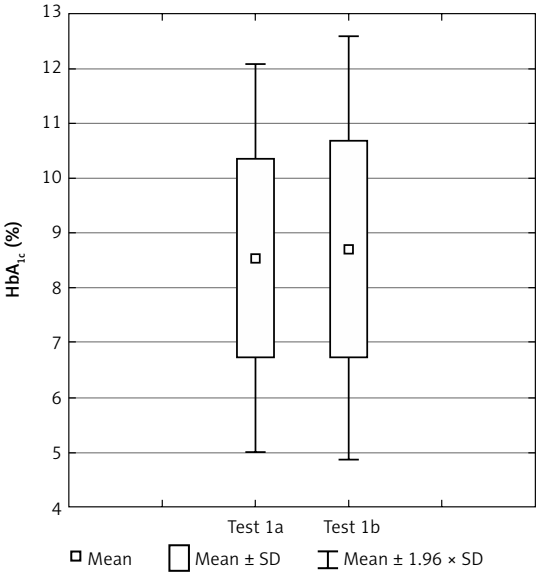

Figure 2. Comparison of glycated hemoglobin values in tests 1a and 1b

Table V. Comparison of nutritional status disorders in tests 1a and 1b

Nutritional status	Test 1a, *n* (%)	Test 1b, *n* (%)
Normal weight	138 (78.8)	139 (79.4)
Overweight	26 (14.9)	24 (13.7)
Obesity	3 (1.7)	5 (2.9)
Underweight	8 (4.6)	7 (4)

(ISPAD) include a target HbA_{1c} of ≤ 7.5% [24]. According to the recommendations of the Polish Diabetes Association, an HbA_{1c} level ≤ 6.5% serves as a detailed criterion of carbohydrate metabolism control in type 1 diabetes in children and adolescents; however, it is difficult to achieve this goal [1]. Indeed, many authors in Poland state that such values of HbA_{1c} values are achieved by only a small number of patients [25].

The current study included patients who reported to the clinic and/or department with specific therapeutic problems. Thus, these results should not be related to or interpreted as the treatment results of the overall population of children treated at the center in which the study was conducted.

In the present study, only 5 (2.2%) children achieved HbA_{1c} values ≤ 6.5%. Thus, for the purposes of statistical analysis, the test group was divided into two groups: one with average control and the other with poor control, using an HbA_{1c} value of 7.5% as the criterion of division to divide the groups.

At time points 1a and 1b, the mean HbA_{1c} values were 8.55 ±1.8% and 8.7 ±1.9%, respectively (p = 0.0005). The patients with average control (HbA_{1c} ≤ 7.5%) accounted for 29% of the patients evaluated at time point 1a and 27.7% at time point 1b.

Similar HbA_{1c} values were demonstrated in patients with type 1 diabetes by researchers at the University of Bergen [26]. In addition, a multicenter collaborative German and Austrian study conducted from 1995 to 2009 demonstrated that the mean HbA_{1c} value was 8.4 ±1.7%, which was higher than the recommended target of 7.5% [23].

One important aspect of treatment is the education of the patient and their relatives, which should prepare the patient for appropriate self-monitoring, thus ensuring the best possible metabolic control and a reduced risk of future microvascular disease [27, 28]. In this study, test questions were used to assessed the knowledge of the parents of children and young adults with type 1 diabetes. The demonstrated level of knowledge was considered good. At time point 1a, the average test result was 14.1 ±2.6, whereas it was 14.8 ±2 at time point 1b, which was significantly higher.

Pietrzak and Bodalski showed that the level of the patients' knowledge and practical skills were positively correlated with the children's age, education and intelligence levels. The authors also found that patients characterized as having good metabolic control demonstrated a higher level of knowledge than those with worse metabolic control [29].

It is believed that insulin therapy in patients with type 1 diabetes may result in excessive weight gain in some cases. Moreover, obesity in individuals diagnosed with type 1 diabetes may be an additional risk factor for cardiovascular disease

[30, 31]. According to the literature, the following factors are the most relevant for the development of obesity: no energy loss through urine with improved glycemic control; the anabolic effect of insulin; an increased intake of high-energy meals caused by the fear of hypoglycemia; the non-physiological, subcutaneous method of insulin administration; and the effect of insulin on the appetite center in the central nervous system [31, 32].

Despite a satisfactory level of knowledge demonstrated by the patients, nutritional disorders were observed, including obesity in 3% of cases and overweight status in 14% of cases. The present study also assessed the nutritional status of children with type 1 diabetes. The mean BMI value at time point 1a was 19.8 ±3.4 kg/m^2 and 20.3 ±3.4 kg/m^2 at time point 1b. These study results are consistent with the results of a Norwegian study [33]. In addition, Luczynski *et al.* assessed nutritional status disturbances in a group of 300 children treated with insulin for at least 1 year. Obesity was observed in 12% and overweight status in 15% of the patients [32].

Araszkiewicz *et al.* demonstrated the efficacy of educational programs and observed a link between metabolic control, the occurrence of retinopathy and albuminuria, and the patient's level of knowledge. According to the authors, improved knowledge about diabetes is the foundation for better metabolic control and can reduce the risk of complications [27]. In our studies, comparison of the knowledge levels of the parents of children and young adults with type 1 diabetes showed that after 1 year, the respondents' test results improved (p = 0.001). Surprisingly, the comparison of metabolic control (HbA_{1c} concentration) at the beginning of the study and 1 year later demonstrated worse control in children over time (p = 0.0005). Most likely, this difference in HbA_{1c} values was caused by socio-psychological factors (e.g., puberty, loss of parent control, peer influence) and was not related to the level of knowledge. Therefore, the following questions arise:

– Why is the level of metabolic control unsatisfactory despite the fact that the level of knowledge is good?
– Why is the level of metabolic control worse after one year and still unsatisfactory despite the fact that the level of knowledge is higher?
– Does the level of knowledge of patients and their parents affect the level of metabolic control?

To examine the underlying causes of the discrepancy between the level of knowledge in the parents of children and young adults (which was higher) and the metabolic control of the tested patients with type 1 diabetes after 1 year (which was worse), one should also consider the individual determinants of mental health of the patients and their ability to maintain self-discipline. In addition, the support that a young patient receives in the fight against a chronic disease and a number of other factors (primarily psychological) that affect the practical implementation of theoretical knowledge during treatment should also be examined. However, these issues do not exclude the role of education in treating this disease, and properly conducted education that results in a higher level of knowledge remains an important part of diabetes treatment.

In a previous study, Brackenridge and Swenson showed that "Discovering Diabetes," a consistently led diabetes education program, influenced the metabolic control of diabetes. The Brackenridge and Swenson program used the discovery learning method, the purpose of which was to develop self-managements skills in the patients and their parents. The authors concluded that by using this program, the patients achieved a significant reduction in HbA_{1c} concentrations, which persisted during and after the completion of education. In particular, the mean HbA_{1c} concentration measured at the beginning of the program was 9.3%, whereas 3 months after the program started, the level fell to 6.2% and remained at 6.6% after 22–26 months.

According to the Polish Diabetes Association, education should be a continual, integral and essential component of the therapeutic approach to diabetes during each follow-up visit. Moreover, education should be implemented in a structured manner based on a general outline that includes education at the onset of therapy and then re-education based on an annual assessment of the training needs of the patient or upon request. Every educational program should also specify the program duration [1].

The aim of patient education is to support the patient in the independent management of diabetes (self-management training) and lifestyle modification associated with the recommended diet and physical activity [1]. In 2000, the CSII method was introduced for diabetes treatment. However, due to the lack of education and treatment standards for this type of insulin therapy, the "Prospective Polish Insulin Pump Therapy Programme" (OPPLP) was initiated [34]. The aim of the OPPLP was to prepare the diabetic centers in Poland for the implementation of insulin pump treatment. This program was conducted in 16 pediatric diabetic centers in two stages: 1) education and 2) clinical data collection and an evaluation of the treatment's effectiveness [35]. The OPPLP was a pilot program and one of the few programs combining the training of educators caring for children with diabetes, the assessment of the effects and quality of the treatment, and the imple-

mentation of new technology in standard medical practice [35].

In the UK and Ireland, an educational course for patients with type 1 diabetes termed "Dose Adjustment for Normal Eating" (DAFNE) was introduced. DAFNE teaches patients to adjust their insulin doses in accordance with their nutritional status and blood glucose concentration [14, 36–38].

Many studies have shown that educational programs are a primary method of supporting the treatment of type 1 diabetes and its complications [2, 14, 15, 22, 37, 39–41]. Currently, therapeutic education is a necessary component of treatment and is implemented together with other strategies for diabetes control.

The role of education in treating type 1 diabetes was emphasized by Rosenbauer *et al.*, who, in a multicenter Austrian and German study, demonstrated significant improvement in the metabolic control of type 1 diabetes in children and young adults over a 10-year period. The researchers linked this improvement to insulin therapy changes, as well as improvements in education [23].

The success of a therapeutic process depends largely on the ability to perform self-management. In the case of children and young people, the patients, as well as their parents and guardians, assume the responsibility for self-management [42].

The effectiveness of treatment depends on the state of knowledge, on the conduct of sick children and young adults and their parents and caregivers, and on patient acceptance of the available methods of self-management and therapy. Indeed, it is known that apart from knowledge, human behavior is affected by a variety of psychological and social factors. Also it should be remembered that achieving good metabolic control also depends on other factors, such as type of diabetes, proper insulin therapy and appropriate self-management, nutritional status, occurrence of lipid disorders, and the presence of additional diseases, such as celiac disease, cystic fibrosis, or frequent infections [1, 43, 44].

The main limitations of this study were as follows: 1) the use of the same questionnaire at time points 1a and 1b (the questionnaire pattern was inadvertently made available to the respondents) and 2) the diversity of the study group, which primarily consisted of parents of children and a small number of young adults.

In conclusion, the parents of children and young adults with type 1 diabetes demonstrated a satisfactory level of theoretical knowledge of therapeutic conduct and self-management principles. The test 1b results demonstrated a higher level of theoretical knowledge in all respondents but poorer metabolic control. Poorer metabolic control in some patients suggests that metabolic control in type 1 diabetes also depends on factors other than education. Further research is necessary to determine these factors.

Conflict of interest

The authors declare no conflict of interest.

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