IMPACT OF PRIMARY CAREGIVER'S KNOWLEDGE ON GLYCEMIC CONTROL PEDIATRIC PATIENTS WITH TYPE 1 DIABETES MELLITUS IN CANTON SARAJEVO, BOSNIA AND HERZEGOVINA

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Abstract: Aim To evaluate primary caregiver's knowledge and impact knowledge on glycemic control in children/adolescents. Methods and participants The research was cross-sectional study conducted from October 23, 2021 year to February 28, 2022 year, in the Canton of Sarajevo. 50 primary caregiver's of pediatric patients up to 18 years old was involved. The Diabetes Knowledge Test was used to assess primary caregiver's knowledge of diabetes. Results Knowledge of the primary caregiver's whose children achieve HbA1c values<7.5% is significantly better than those whose children have HbA1c value >7.5% in general knowledge (p=0.003*), total (p=0.014*), while knowledge of insulin did not differ (p=0.865). Conclusion Continuous education of nurses who are key in educating patients and diabetes specialist nurses, especially pediatric specialist nurse is needed to provide effective health care. It would also be of paramount importance to recognize the need for health professionals in the field of nutrition who would provide health services to these patients, as part of the diabetes health care team. Health service providers should regularly assess the knowledge of pediatric patients and their parents about diabetes and self-help management skills, especially in patients who do not achieve optimal HbA1c values, in order to improve knowledge levels and improve skills for disease management.

Keywords: education, nutritionist, diabetes specialist nurse

1. INTRODUCTION

Type 1 Diabetes mellitus (T1DM) is a condition that is difficult to control only with medicines, but with appropriate care and support, children and adolescents with T1DM can have a long and fulfilling life (Los & Wilt, 2021). Selfmanagement of T1DM is a challenging and complex physical, emotional, social and intellectual process for children, adolescents and their parents. Education of self-control patients is key to controlling diabetes, combined with family support (Thompson et al, 2020). Standards of education and support for diabetes self-management recognize education as an integral component of caring for all people with diabetes (Kumah et al, 2020). Parent education is the professional responsibility of most health professionals with the necessary information to make it easier for them to take on the role of childcare (Vissarion et al, 2014). Changing lifestyle to reach good metabolic control and achieving the goals proposed in treating diabetes requires investing additional efforts by educators for diabetes, nutritionists and people with diabetes (Araújo et al, 2018). Education should be comprehensive and involves observing, monitoring and identifying symptoms in inadequate glycaemia control (Knafl et al, 2013). The role of a diabetes specialist nurse is crucial for patients and families to establish confidence in health service providers and to make maximum health promotion (Vissarion et al, 2014). They helps parents in the role of caring for their child, providing the right information and teaching the skills and techniques they need to treat this chronic disease (Thompson et al, 2020). Also, diabetes specialist nurses s bridge the gap in expertise and knowledge among teams providing patients and health professionals who are not specialists in this field with specific diabetes

education. This specialist role is known to have a positive effect on the outcomes of patients with diabetes (Lawler et al, 2019). Improving parent's knowledge and education can improve glycemic control and ultimately reduce acute and chronic complications of diabetes in children. For health professionals to make it easier for their mother to deal with diabetes, they must first determine which aspects of the disease are the most difficult (Al-Odayani et al, 2013). Occasional assessments of parent's knowledge can play a role in identifying and addressing knowledge gaps, and it is important to assess the knowledge of parents of children and younger adults with T1DM, as well as the impact of knowledge on the degree of metabolic control (Stefanowicz et al, 2018). Results on knowledge of diabetes, obtained by the Diabetes knowledge test (DKT) questionnaire, can help design tailored interventions that address specific areas of patient needs and improve the behavior of self-care for diabetes. In addition, when creating an education plan, socioeconomic conditions of patients should also be taken into account, in order to help them successfully manage their disease (Vivian et al, 2014). The aim of the article was to evaluate primary caregiver's knowledge and impact knowledge on glycemic control in children/adolescents, to evaluate impact of primary caregiver's age and education degree on knowledge as well impact of the child and adolescent's disease duration on primary caregiver's knowledge.

2. PATIENTS AND METHODS

Patients and study design

The research was cross-sectional study conducted from October 23, 2021 year to February 28, 2022 year, in area of the Canton of Sarajevo, inside Association of Diabetic Children and Youth of Canton Sarajevo. The survey involved 50 primary caregiver's of pediatric patients up to 18 years old. After the association's consent was obtained, members' data were accessed, after which appointments for surveying respondents were scheduled. Subjects were explained to the objectives of the study, and voluntary oral and written consent was collected from the primary caregiver's for participation in the survey. Criteria for inclusion in the study were that parents and they children and adolescents are members of the Association of Diabetic Children and Youth of the Canton of Sarajevo, age of child and adolescents to 18 years old, duration of disease longer than six months, and that parents voluntarily agreed that they and their children participate in the research.

Methods

After receiving consent, a survey was carried out. During the research, parents provided a copy of the last child/adolescent values of glycolyzing hemoglobin (HbA1c). Optimal glycemic control was considered HbA1c <7.5% (Anderson et al, 2017). Primary caregiver's age and education degree and child and adolescent's disease duration were collected from primary caregiver. The Questionnaire Research and Training Center Diabetes Knowledge Test was used to assess parents knowledge of diabetes. The questionnaire contains 23 questions of knowledge about diabetes and consists of two components: a general test of 14 items and 9 questions of knowledge about insulin use (Fitzgerald et al, 1998). Since the test is not available in Bosnian/Serb/Croatian language, the questionnaire has been translated and adapted for the purposes of this research. During the research, the Code of Ethics for research with children and children in Bosnia and Herzegovina was respected in accordance with the UN Convention on the Rights of the Child and with the aim of protecting children from any abuse. The research was approved by the Ethics Committee of the Faculty of Health Studies of the University of Sarajevo. The PhD project approved by the Senate of the University of Sarajevo, noting that it can be carried out with the written consent of the parents. All parents involved signed a written consent to participate in the survey.

Statistical analysis

After the survey was carried out, the data collected was entered in an electronic database created in Microsoft Office Excel 365. Category variables are displayed by frequency—as an absolute number or as a percentage per column (study group). The results are presented with the following parameters: mean and standard deviation, descriptive statistical view with interquartile range. The Chi-square test—was used in the study of the existence of a difference between expected and observed values in one or more categories in contingency tables. To test differences in the sum of points, an ANOVA test was used (in three groups), i.e. a t- test when testing the differences between the two groups, if the data were parameter distributed. A Pearson correlation—test, whose correlation coefficient is graduated to the following limits, was also used: $0 \text{ to} \pm .19 \text{ very weak}; \pm .20 \text{ to} \pm .39 \text{ weak}; \pm .40 \text{ to} \pm .59 \text{ medium}$ strong; $\pm .60 \text{ to} \pm .79 \text{ strong} \pm .80 \text{ to} 1.0 \text{ very strong}$ connection. The correlation of the variable was graphically accompanied by a scatter plot diagram. Multiple linear regression was used to test and model relationships between one variable marked with Y, and one or more variables to X. A statistical program of IBM SPSS Statistics 26.00 (IBM Corporation, Armonk, New York) was used for statistical processing. Statistical significance is set with a p value < 0.05. The results of the study are presented textually, in tables—and figure.

3. RESULTS

Of the total number, 49 (98%) primary caregivers were children and adolescents' mothers and 1 (2%) was father. All participants 50 (100%) and their children received counselling and education services in the institution of the tertiary level of health care. Parents' knowledge was examined through questions about general knowledge and knowledge of insulin, on the basis of which the total knowledge of parents was created. Caregivers in the general part of the questionnaire were found to answer on average $84.71\pm11.36\%$. On average, $94.22\pm6.82\%$ answered insulin questions. Overall knowledge showed that on average $88.43\pm7.98\%$ of respondents answered. Parents answered insulin-related questions significantly better than issues related to general diabetes care p<0,0001 (Table 1).

Table 1. Analysis of parents' knowledge

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	Correct answers	Mean	SD	Median	Per.25	Per. 75	Min.	Max.
Total knowledge	N	20,3	1,8	20,5	20,0	21,0	13,0	23,0
	%	88,43	7,98	89,13	86,96	91,30	56,52	100,00
General knowledge*	N	11,9	1,6	12,0	11,0	13,0	5,0	14,0
	%	84,71	11,36	85,71	78,57	92,86	35,71	100,00
Knowledge of _ insulin*	N	8,5	0,6	9,0	8,0	9,0	7,0	9,0
	%	94,22	6,82	100,00	88,89	100,00	77,78	100,00

^{*} t=-4,634; p<0,0001

In the general part of the questionnaire, we detected 7/14 questions to which respondents give incorrect answers. The highest number of dietary issues 6/7 (Table 2), has been detected. Insulin questions were detected by 1/9 questions answered incorrectly by 32% of respondents (Table 3).

Table 2. General knowledge issues that have affected the reduction of general knowledge

Questions with incorrect answers	N	%	X ²	$\mathbf{p}^{\mathbf{A}}$	Impact on general knowledge
Average general knowledge assessment	42/50	84,7	-	-	-
Average misfits	8/50	15,3	-	-	-
Which should not be used to treat a low blood glucose?	25/50	50,0	12,157	<0,001	$\downarrow\downarrow\downarrow$
What effect does unsweetened fruit juice have on blood glucose?	15/50	30,0	28,386	<0,001	$\downarrow\downarrow\downarrow$
Which of the following is a "free food"?	14/50	28,0	30,411	<0,001	$\downarrow\downarrow$
Which of the following is a highest in fat"?	11/50	22,0	37,011	<0,001	$\downarrow\downarrow$
Eating foods lower in fat decreases your risk for:	11/50	22,0	37,011	<0,001	$\downarrow\downarrow$
Which of the fallowing is highest in carbohydrates?	9/50	18,0	41,891	<0,001	\downarrow
Which is the best method for home glucose testing?	9/50	18,0	41,891	<0,001	\downarrow

Table 3. Insulin knowledge issues that have affected the reduction of overall knowledge

Questions with incorrect answers	N	%	\mathbf{X}^2	p	Impact on total knowledge
Average special knowledge rating	47/50	94,22	-	-	-
Average misanswer	3/50	5,78	-	-	-
Signs of ketoacidosis (DKA) include	16	32	38,94	<0,001	$\downarrow\downarrow\downarrow$

There was no difference in the knowledge of the primary caregiver in relation to age, education degree, or duration of the disease (Table 4). It was found that the knowledge of the primary caregiver's whose children achieve HbA1c values<7.5% is significantly better than those whose children have HbA1c value >7.5% in general knowledge (p=.003), total (p=.014), while knowledge of insulin did not differ (p=.865) (Table 4).

Caracteristic of the subject	Cases N=50 (%)		in relation to knowledge Knowledge			
		General	About insulin	Total Mean (SD)		
Age		Mean (SD)	Mean (SD)			
<40	21(42,0)	83,12 (13,33)	94,95 (6,62)	87,75 (9,36)		
>40	29 (58,0)	85,97 (9,62)	93,65 (7,05)	88,98 (6,85)		
t; p		879; .384	.664; .510	536; .594		
Education						
Basic	2 (4,0)	88,89 (0,00)	92,86 (10,10)	91,30 (6,15)		
High school	33 (66,0)	82,47 (12,38)	93,94 (7,40)	86,96 (8,56)		
Faculty degree	15 (30,0)	88,57 (7,54)	95,56 (5,63)	91,30 (6,15)		
F; p		2.115; .132	.923; .405	1.712 .192		
HbA1c (child)						
<7,5%	32 (64,0)	88,17 (7,83)	90,49 (6,29)	94,10 (6,90)		
>7,5%	18 (36,0)	78,57 (14,07)	94,44 (6,87)	84,78 (9,46)		
t; (p)		3.110; .003*	171; .865	2.560; .014*		
Duration of disease						
<2 Years	9 (18,0)	85,71 (9,45)	95,06 (5,86)	88,63 (10,58)		
2-5 year	13 (26,0)	84,07 (15,75)	95,73 (7,23)	89,37 (6,56)		
5 year	38 (76,0)	84,69 (9,86)	93,25 (6,99)	88,04 (7,26)		
F (p)		.054; .948	.657; .523	.096; .909		

^{*}significantly

The connection of general and total knowledge to HbA1c level was also confirmed by Pearson correlation: general knowledge (r=-.406; p=.003); total knowledge (r=-.354; p=.012); it was not related to knowledge of insulin (r=-.063; p=.587) (Figure 1).

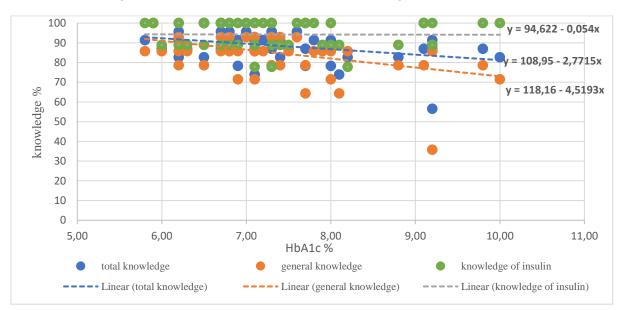


Figure 1. Relation between mother diabetic knowledge and blood HbA1c level

4. DISCUSSION

In the canton of Sarajevo, the public health system is complex, divided into three levels: the primary, secondary and tertiary level of health care. Primary public health care is in the area of local communities and was conceived to bring health care closer to patients. Tertiary level facility is an institution for hospitalized patients, but also organizes its work through various specialist and subspecialist services in outpatient conditions. In addition, it is an institution that provides services for patients from other Cantons, not only for patients from canton of Sarajevo.

Pediatric clinic is part of tertiary health care, which is the only institution in the canton of Sarajevo that provides health services for education and counselling to these patients. This is also confirmed by the fact that all parents 50 (100%) in our survey replied that health education and counselling services related to the disease of their children/adolescents were obtained at the tertiary healthcare facility.

The education program for patient self-efficiency is a holistic approach that includes human factors, organizational characteristics and interventional characteristics, interdisciplinary approach and didactic session held by doctors, nurses and dietitians (Padda et al, 2022). For successful diabetes management, education is crucial, and for promoting workshop health or demonstrations are essential (Rochmah et al, 2021). Continuous education is usually carried out in outpatient conditions, but is also available in hospitals. Continuous educational programmes should also include interactive educational tools available for children and adolescents with T1DM. In order to provide effective health care to children and adolescents with DMT1, there is a need for additional standardized training on diabetes and among students who are educated for future nurses, as well as continuous education of nurses in practice (Kobos et al, 2020).

All healthcare providers should refer people with diabetes to individual nutritional therapy, provided by a registered nutritionist/dietitian trained to provide nutritional therapy specific to diabetes (American Diabetes Association, 2021), but in public healthcare the canton of Sarajevo the role of nutritionist has not yet been recognized and the services of the nutritionist are not available.

In the institutions with lack of pediatric dietitians and poor dietary support is low level of knowledge about carbohydrates among children and their parents, despite knowledge of carbohydrates improving the performance of medical treatment T1DM and is a fundamental topic of education after a verifiable diagnosis of DMT1 (Stefanowicz et al. 2018).

In our study we observed that the primary caregiver's knowledge was assessed with good average grades 88,43% (min: 56,52%; max. 100,00%), which is expected, as most of children 32/50 (64,00%), achieved optimal HbA1c values <7,5%. Nevertheless, the results of our research have proven that better knowledge of diabetes have parents whose children/adolescents achieve optimal HbA1C values <7,5% compared to those with HbA1C values greater than >7,5%. This research coincides with previous research aimed at investigating the impact of mothers' knowledge on better glycemic control (Al-Odayani et al, 2013; Tahirovic & Toromanovic, 2010; Noorani et al, 2016)

Noorani M. et al (2016) has proven that primary caregiver's knowledge is associated with HbA1C (r2 = 0.07, p value = 0.036). In this study, the prescient assessment of parents diabetes knowledge was $70 \pm 15\%$, which is significantly lower than in our research. Such results are also likely related to the absence of optimal HbA1C values in this study (average HbA1c was $11.1 \pm 2.1\%$), unlike our subjects where most subjects achieve HbA1C <7,5 %, which can also be considered evidence that the mother's knowledge is significantly linked to glycemic control in children.

In our study, there was no significant difference in the knowledge of the primary caregiver according to the age, same reported in another study (Tahirovic & Toromanovic, 2010). Parents with basic education showed better knowledge $91,30\pm6,15\%$ compared to the parents with high school $86,96\pm8,56\%$, but it was not statistically significant although in some studies it was shown that the professional education of mothers was associated with knowledge and that mothers with lower levels of education have less knowledge of diabetes (Al-Odayani,et al, 2013; Tahirovic & Toromanovic, 2010), which is not consistent with our study. Other research have reported that subjects with lower educational levels have achieved worse results in the survey, but the mean levels of HbA1c their children were lower (Alonso et al, 2016).

Due to the contingency in the results of the research of the aforementioned studies, we can assume that knowledge of diabetes is associated with greater parents motivation to learn about the control of their child's disease.

Tahirovic and Toromanovic (2010) also proved that the mother's knowledge was associated with glycemic control where the mother's higher knowledge was significantly associated with lower HbA1c (r=-0.286, p= 0.044), which is consistent with our research. In addition, this research coincides with our research because there were also no significant differences in mothers' knowledge compared to the length of the duration of the disease.

In addition to this study, research results that the knowledge is associated with glycemic control, coincide with research by Al-Odayani et al (2013), conducted in Saudi Arabia. The study showed that there was a significant link

between mothers' knowledge of diabetes and HbA1c levels (p<0.05), indicating that greater knowledge eventually leads to greater control of HbA1c in children.

The analysis of the questionnaire indicates the need for improved education, especially for those parents, whose children/adolescents do not achieve optimal HbA1c values. Education should improve parents knowledge with an emphasis on controlling glycaemia in home conditions, and identifying symptoms of hypo and hyper glycaemia, so that they can help their child/adolescent in a timely manner. We found that 16 (32%) primary caregivers didn't known about symptoms of ketoacidosis.

Education on diabetes management consists of complex information at a time when parents are still emotionally wear with shock and become emotionally upset when they find out that their child has T1DM, but they are expected to quickly learn functional diabetes management, and may be hospital discharge before they are ready to take care of their child (Sullivan-Bolyai et al, 2014).

Diabetes specialist clinical nurses must work with parents to ensure continued childcare when discharged from hospital. Consequently, nurses are needed certified in this field to educate patients and future patients about diabetes, and discuss diabetes prevention and care (Vissarion et al, 2014). Study O'Hagan et al (2010), highlights the importance of a pediatric diabetes specialist nurse specializing in diabetes, which makes increased contact between the institution and the child/family. Their results indicate that recognizing the position of a pediatric nurse specializing in diabetes achieves better HbA1c values in children, reduces the length of stay in the hospital newly diagnosed, and improves disease control especially in children over 10 years of age. A pediatric nurse specializing in diabetes can affect harmful behavioral factors that occur in adolescence.

Although studies highlight diabetic specialist nurse as important factor to provide effective health care (Thompson et al, 2020; Vissarion et al, 2014; Lawler et al, 2019; O'Hagan et al 2010), that they are cost-effective and have been associated with increased patient satisfaction (Lawler et al, 2019), specialization of nurses in our country remains not recognized.

Although we did not assess the degree of diabetes education by participants, general knowledge of diabetes care in parents whose children/adolescents do not achieve optimal HbA1c values<7.5% is significantly lower than those of parents whose children had optimal HbA1c values. Since all subjects received education related to diabetes in a tertiary level of healthcare, most likely subjects participated in education in the form of formal classes of diabetes education that covered several aspects of self-care diabetes to the fullest extent at the very beginning of the disease or when there was a changes in the way diabetes is treated.

With insight into the structure of Pediatric Clinic 1, available on internet, and the organization of the department of endocrinology and diabetes, we found that five departmental and one main nurse were employed in the hospital part. The structure states that only one nurse is employed in the advisory for endocrinology and diabetes, and we have not found that a nutritionist is involved in the health team that cares for these patients, which may explain the lack of knowledge of some participants about the importance of the type of diet in the treatment of diabetes (https://www.kcus.ba/pedijatrijska-klinika/).

In the examination of parents knowledge, we observed that no significant differences in the knowledge of parents during the time.

Since only one nurse works at the Diabetes and Endocrinology Advisory (https://www.kcus.ba/pedijatrijska-klinika/), it is not realistic to expect that repetitive education is of a recurring character, especially because the counseling room is not intended only to work with patients who have T1DM.

In educating patients, among other health professionals, the role of registered nutritionist is key. Nutritionist support is necessary when diagnosing, but if necessary throughout life. Individual nutritional therapy provided by a registered nutritionist is associated with a decrease in HbA1c by 1.0-1.9% in patients with T1DM (American Diabetes Association, 2021). Education on nutrition and lifestyle changes should be individual in a patient-oriented way. Evidence-based diet strategies are effective if feasible for patients for whom they are designed. Pickiness in patients should be taken into account, as well as compatibility with local culture and resources (Cristello et al, 2022). Children and those who care for them can learn to estimate how many grams of carbohydrates cover 1 unit of insulin, but they need continuous education (Tascini et al, 2018).

After carbohydrate counting training, patients should understand the relationship between insulin, nutrition and exercise. Most importantly, these trainings should be repeated occasionally, and patients should be tested for carbohydrate counting skills (Bayram et al, 2020).

Results of this study and some others studies mentioned (Al-Odayani et al, 2013; Tahirovic & Toromanovic, 2010; Noorani et al, 2016) emphasizes that improved mothers knowledge about diabetes, as children's primary caregivers, is the key role to achieve better glycemic control in the child.

Mothers, et home, are their children nurses and dietitians (Tahirovic & Toromanovic, 2010), so in order to manage the disease, they need the support of both, dietitians and nurses. It is important to highlight the importance of

continuous education of nurses who are key in educating patients and the need to diabetes specialist nurses, due to the specificity that is characteristic of children and adolescents, which are psychophysical changes through which these patients undergo ages of growth and development. A special emphasis should be placed on the need for a pediatric diabetes specialist nurse.

In addition, the education of nurses employed in primary health care, in order to relieve tertiary levels of health care and allow patients with chronic diseases to receive outpatient education and counselling services in their local community, which would allow them to receive more accessible health care and better monitoring between regular visits to the Clinic.

It would also be of paramount importance to recognize the need for health professionals in the field of nutrition who would provide health services to these patients, as part of the diabetes health care team. Health service providers in the Canton of Sarajevo and other parts of Bosnia and Herzegovina should regularly assess the knowledge of pediatric patients and their parents about diabetes and self-help management skills, especially in patients who do not achieve optimal HbA1c values, in order to improve knowledge levels and improve skills for disease management.

TRANSPARENCY DECLARATION

Competing interests: none to declare.

ACKNOWLEDGMENTS

This manuscript presents part of PhD thesis in progres. Faculty of health science University of Sarajevo. "Quality of life children and adolescents with type 1 Diabetes mellitus". We want to thank the Association of Diabetic Children and Youth of the Canton of Sarajevo and all parents who voluntarily agreed that they and their children participate in the research.

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