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Educational needs of people with type 1 diabetes mellitus and their parents: A cross-sectional study

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Abstract

Aims: To investigate the educational needs of type 1 diabetes patients and their parents.

Design: A cross-sectional design was employed.

Methods: Data were collected via an online survey and analysed by descriptive statistics and an independent t-test. Statistical analyses were performed using IBM SPSS version 25.0. Participants comprised type 1 diabetes patients (100) and their parents (93).

Results: Complications management, disease characteristics and exercise were found to be the highest educational needs of type 1 diabetes patients and their parents. The following educational needs differed between patients and parents: complication management, exercise, continuous management, psychosocial needs and risk factors. Regarding psychosocial needs, social life was the most needed in terms of disease management and how to have a social life with the disease.

KEYWORDS
chronic illness, diabetes mellitus, education, type 1 parents

1 | INTRODUCTION

1.1 | Background

Type 1 diabetes mellitus (T1DM) is a chronic illness that requires continuous adaptation and management; the management process—encompassing diet, insulin injections and blood glucose monitoring—is a complex and challenging one (Kumar et al., 2015). Further, disease management is a daily endeavour that leads to changes in the overall daily routine and requires parents' and family's support. Due to the need for lifelong management, diabetes education for patients and their parents is an important component of disease management (American Diabetes Association, 2009). Diabetes education is focused on imparting knowledge and promoting effective disease management (Choi & Jung, 2010); therefore, education programmes must be tailored to the needs of patients and their parents. As education that addresses needs can not only increase knowledge but also improve treatment adherence and self-care (Norris et al., 2002), it is important to identify specific topics to fulfil patients' and families' educational needs.

Although patients with T1DM and their parents are on the journey together, they have different roles and stances and thus may have different situational and educational needs. First, previous studies on patients with T1DM showed that this patient population suffers from severe hypoglycaemia, hospital admission due to complications and poor quality of life (Kristensen et al., 2014), in addition to various psychosocial challenges, the most common of which are depression and anxiety (Al-Khurinej, 2007). Next, parents of patients with T1DM felt burdened due to having to adjust the family's lifestyle because of their child's condition and engage in daily management,

such as choosing the appropriate foods, measuring blood glucose and administering insulin injections (Keklik et al., 2020). As such, parents may need educational support to be able to manage the disease effectively, provide psychosocial support to the child and overcome their own psychosocial challenges. Furthermore, adverse psychosocial impacts of T1DM affect disease management, including blood glucose control; therefore, it is also important to identify the educational needs pertaining to psychosocial problems.

A study on empathic accuracy, which refers to the accuracy of parents' empathy toward their child's condition, revealed that parents may show poor empathic accuracy for their child's negative emotions and suggested that enhancing parents' empathic accuracy is crucial to promoting mental and physical health of children with T1DM (Main et al., 2022). In general, the same educational content is to be used for patients with T1DM and their parents, but identifying the differences in their educational needs would enable the development of tailored education. Furthermore, as a more comprehensive, personalized diabetes education for parents delivered by healthcare professionals is believed to help reduce parents' burden and worries (Commissariat et al., 2020), it would be more effective to accurately identify the learners' needs and provide education based on priorities. Research on educational needs can also present foundational data for providing patient-centred, individualized education. High educational needs for a certain topic means that the topic is not adequately taught, there is great fear about the topic, or patients consider the topic as modifiable through education. Given that educational needs do not differ depending on the current level of knowledge of diabetes (Park & Oh, 2014), low educational needs cannot be interpreted as indicating a high level of diabetes knowledge. In other words, examining educational needs allows for diverse interpretations and sheds light on patients' current hardships and perceptions.

1.2 | The study

1.2.1 | Aims and objective

In this context, this study aims to investigate the educational needs of patients with T1DM and parents of patients in terms of disease management and psychosocial aspects. The study attempts to identify the differences in patients' and parents' educational needs by topic and organize these needs by priority to present useful baseline data for educational programmes.

2 | METHODS

2.1 | Design

This was a cross-sectional descriptive study to identify the diabetes education needs of T1DM patients and parents of T1DM patients.

2.2 | Instrument with validity and reliability

2.2.1 | Participants' characteristics

Age, duration of disease and recently measured HbA1C levels were filled in directly as numbers and percentages. Religion, job, complications, diabetes education and experience of diabetes camp were responded to with 'yes' or 'no'. Sex, a categorical variable, was responded to as 'male' or 'female', and source of diabetes information was marked as 'personal' if information was obtained through the Internet, books or personally and 'expert' if obtained through education from experts such as doctors or nurses in hospitals or public health centres.

2.2.2 | Diabetes education needs

A diabetes education needs questionnaire was developed based on a literature review of previous studies, and its content validity was reviewed by an endocrinologist, two diabetes nurses and a nursing professor. It comprised a total of 64 items and 8 subdomains. Diabetes education needs consisted of characteristics of the disease (4 items), risk factors (9 items), medication (6 items), diet (10 items), physical activity and exercise (5 items), continuous management (11 items), complication management (8 items) and psychosocial needs (11 items). The model fit index of the measurement model was confirmed by confirmatory factor analysis and CMIN/DF = 1.31 ($p = 0.207$), which satisfied the criterion of less than 2. In addition, the model fit index was acceptable with a goodness of fit index (GFI) 0.980, comparative fit index (CFI) 0.997, Tucker–Lewis index (TLI) 0.994 and root mean square error of approximation (RMSEA) 0.040. The Cronbach's α values indicating reliability of the subdomains were 0.891, 0.868, 0.888, 0.954, 0.921, 0.931, 0.976 and 0.976 for disease characteristics, risk factors, medication, diet, physical activity and exercise, continuous management, complication management and psychosocial needs, respectively; Cronbach's α for the overall scale reliability was 0.982.

2.3 | Sampling and recruitment

2.3.1 | Sample size and power

The sample size was calculated using G Power 3.1.9.4 (Faul et al., 2009) to determine the minimum sample size required to perform an independent t-test, with a two-tailed significance level (α) of 0.05, statistical power ($1-\beta$) 0.90 and median effect size (d) 0.5 (Cohen, 1988). The number of required participants was computed as 86 in each group, for a total of 172. Efforts were made to avoid potential selection bias in participant recruitment. Finally, a total of 193 participants (100 T1DM patients, 93 parents of T1DM patients) were included in this study.

2.4 | Population and sample

The participants included T1DM patients and parents of T1DM patients who were enrolled as members of a T1DM online community.

2.4.1 | Data abstraction

Inclusion and exclusion criteria

Patients were selected on the criteria that they had been diagnosed with type 1 diabetes and managed diabetes at home. For parents, the criteria were that their children were T1DM patients with self-managed diabetes and were not hospitalized due to complications. From the families of T1DM patients, only one of the T1DM patients or their parents were allowed to respond to the questionnaire, and both the T1DM patient and their parent voluntarily accessed the URL of the online survey to read and respond to the questionnaires.

2.4.2 | Data collection

Data were collected through an online self-report questionnaire from 12 to 27 July 2021 in South Korea. The researchers explained the purpose and procedure of the study to the web managers of the T1DM online communities and asked for their cooperation in obtaining consent from T1DM community members. Information about the survey, such as the purpose, procedure, participation method, rewards, survey URL, researcher contact information and so on, was posted on the T1DM online community website.

2.4.3 | Data analysis

The collected data were analysed using SPSS Statistics (version 25.0, SPSS, IBM). Participants' characteristics were analysed using frequencies, percentages, means, standard deviations and minimum and maximum values. Diabetes education needs were analysed by means, standard deviations and minimum and maximum values using descriptive statistics. The differences in diabetes education needs of T1DM patients and parents of TIDM patients were analysed by an independent *t*-test. Diabetes education needs of the two groups were compared with the mean and standard deviation of the subitems for each diabetes education need. The cutoff for statistical significance in the present study was $p < 0.05$.

2.5 | Ethical considerations

The participants were informed about the research purpose, study procedure and rights of the participants and anonymity was guaranteed. In addition, only individuals who read the online consent form that included a description of the study and voluntarily consented to participate in the study were able to participate in the survey. Although this study did not pose any physical or mental harm to participants, every effort was made to protect the participants' rights. In addition, the participants were informed that they could withdraw at any time if they wished to do so, that the research was being carried out anonymously to avoid dissemination of personal information, and that the data would not be used for any purpose other than this research.

3 | RESULTS

3.1 | Subjects

The participants in this study included 100 T1DM patients and 93 parents of T1DM patients. The patients' average age was 21.85 (SD 5.48) years, including 63 (46.3%) female patients, 73 (59.8%) who were not religious and 89 (59.7%) who were working; whereas, the parents of T1DM patients were aged 45.83 (SD 4.25) years, including 73 (53.7%) mothers, 49 (40.2%) who were not religious and 60 (40.3%) who were working. Among all participants, the average duration of the disease was 7.47 (SD 5.68) years and 20 (10.4%) of them reported complications. The average HbA1c measured recently was 7.39% (SD 1.43). Among the participants, 178 (92.2%) had received diabetes education and 59 (30.6%) had experience of participating in a diabetes camp. Furthermore, 141 (73.1%) participants obtained diabetes information from 'personal' sources, such as the Internet, books, diabetes communities and acquaintances (Table 1).

3.2 | Differences in the diabetes education needs of T1DM patients and parents of T1DM patients

T1DM patients reported the highest education needs in the order of complication management, characteristics of the disease, physical activity and exercise and medication; the parents of T1DM patients reported the highest education need for complication management, followed by continuous management, physical activity and exercise and characteristics of the disease. Scores for diabetes education needs were higher in the parent group compared with the patient group for all subitems. There was no difference in the overall education needs score between the two groups ($t = -0.92$, $p = 0.358$); however, when compared by category, diabetes education needs for complication management ($t = -2.33$, $p = 0.021$), physical activity and exercise ($t = -2.13$, $p = 0.034$), continuous management ($t = -2.87$, $p = 0.005$), diet ($t = -2.13$, $p = 0.035$), psychosocial needs ($t = -3.45$, $p = 0.001$) and risk factors ($t = -2.22$, $p = 0.028$) were higher in parents of T1DM patients than in T1DM patients, and the difference was statistically significant (Table 2).

TABLE 1 Participants' characteristics ($N = 193$).

Characteristics	Total ($N = 193$)	T1DM patients ($n = 100$)	Parents of T1DM patients ($n = 93$)
	N (%) or mean SD (min. – max.)		
Age (years)	33.40 ± 12.98 (13–57)	21.85 ± 5.48 (13–30)	45.83 ± 4.25 (38–57)
Sex			
Male	57 (29.5)	37 (64.9)	20 (35.1)
Female	136 (70.5)	63 (46.3)	73 (53.7)
Religion			
No	122 (63.2)	73 (59.8)	49 (40.2)
Yes	71 (36.8)	27 (38.0)	44 (62.0)
Job			
No	44 (22.8)	11 (25.0)	33 (75.0)
Yes	149 (77.2)	89 (59.7)	60 (40.3)
Duration of disease (year)	7.47 ± 5.68 (0–24)	8.12 ± 6.28 (0–24)	6.77 ± 4.88 (0–19)
Complication			
No	173 (89.6)	85 (49.1)	88 (50.9)
Yes	20 (10.4)	15 (75.0)	5 (25.0)
HbA1c (%)	7.39 ± 1.43 (5.2–15.0)	7.30 ± 1.28 (5.2–11.2)	7.48 ± 1.58 (5.8–15.0)
Diabetes education			
No	15 (7.8)	7 (46.7)	8 (53.3)
Yes	178 (92.2)	93 (52.2)	85 (47.8)
Experience of diabetes camp			
No	134 (69.4)	73 (54.5)	61 (45.5)
Yes	59 (30.6)	27 (45.8)	32 (54.2)
Source of information			
Expert	52 (26.9)	37 (71.2)	15 (28.8)
Personal	141 (73.1)	63 (44.7)	78 (55.3)

Abbreviations: HbA1c, Glycated haemoglobin; Max, Maximum; Min, minimum; SD, standard deviation; T1DM, type 1 diabetes mellitus.

3.3 | Ranking of subitems of diabetes education needs

In the category of complication management, the diabetes education needs of T1DM patients were ranked in the order of retinopathy, complication types and regular check-up, while those of the parents of T1DM patients were ranked in the order of retinopathy, regular check-up, nephropathy and neuropathy.

In characteristics of the disease, diabetes management goals were the highest ranked diabetes education need by both groups; the second highest education need for T1DM patients was pancreas and insulin function, and for the parents of T1DM patients, it was diabetes progression.

In physical activity and exercise, diabetes exercise during complications and exercise method were the first and second priority education needs, respectively, for both groups.

In continuous management, the latest trends and continuous blood glucose meter were the first and second highest education needs, respectively, for both groups. Sick day management was ranked the third highest educational need by T1DM patients, and foot care was the third highest education need for parents. While T1DM patients rated pancreas transplant as the lowest educational need, parents of T1DM patients rated vaccination as the lowest.

In medication, blood sugar-affecting drugs were the first priority for both groups; insulin dose adjustment was the second priority for T1DM patients and insulin side effects were the second priority for parents of T1DM patients. The remaining subcategories were given similar ranks by the two groups.

In diet, T1DM patients reported high education needs in the order of food management for complications, special day meal management and the importance of diet; parents of T1DM patients ranked high education needs in the order of free food, glycaemic index and food plan using food exchange table. Whereas, for T1DM patients, food plan using food exchange table was the lowest education need.

In psychosocial needs, the categories of social life, love and marriage were ranked as high education needs by both groups. The

TABLE 2 Difference in diabetes education needs between T1DM patients and parents of T1DM patients ($N = 193$).

		Total ($N = 193$)		T1DM patients ($n = 100$)	Parents of T1DM patients ($n = 93$)	
Ranking	Categories	Mean ± SD	Min – max.	Mean ± SD	Mean ± SD	t (p)
1	Complication management	3.50 ± 0.60	1.0–4.0	3.41 ± 0.67	3.61 ± 0.50	−2.33 (0.021)
2	Characteristics of the disease	3.46 ± 0.55	1.0–4.0	3.43 ± 0.54	3.51 ± 0.57	−1.01 (0.315)
3	Physical activity and exercise	3.44 ± 0.58	1.0–4.0	3.36 ± 0.64	3.53 ± 0.49	−2.13 (0.034)
4	Continuous management	3.44 ± 0.54	1.3–4.0	3.34 ± 0.58	3.56 ± 0.47	−2.87 (0.005)
5	Medication	3.42 ± 0.58	1.0–4.0	3.35 ± 0.57	3.49 ± 0.58	−1.62 (0.108)
6	Diet	3.36 ± 0.62	1.0–4.0	3.27 ± 0.68	3.46 ± 0.53	−2.13 (0.035)
7	Psychosocial needs	3.21 ± 0.69	1.0–4.0	3.05 ± 0.73	3.38 ± 0.59	−3.45 (0.001)
8	Risk factors	3.18 ± 0.59	1.2–4.0	3.09 ± 0.59	3.28 ± 0.58	−2.22 (0.028)
Total education needs		26.85 ± 4.04	11.1–32.0	26.44 ± 4.00	27.08 ± 4.06	−0.92 (0.358)

Abbreviations: Max, Maximum; Min, minimum; SD, standard deviation; T1DM, type 1 diabetes mellitus.

third-ranked diabetes education need for T1DM patients was prejudice and that for parents of T1DM patients was pregnancy and childbirth. Furthermore, sibling conflict was the lowest ranked education need among T1DM patients, and early childhood growth and development was the lowest among parents of T1DM patients. In the category of risk factors, treatment of hyperglycaemia symptoms was rated the highest educational need by both groups (Table 3).

4 | DISCUSSION

Our results showed that, overall, parents of patients with T1DM had higher educational needs than the patients themselves. Considering previous findings that education needs are higher among those with a fear of hypoglycaemia (Abitbol & Palmert, 2021), the current results suggest that parents have greater fear and concern over blood glucose management. Moreover, consistent with previous reports that parents are interested in learning about a variety of topics, including the child's overall diabetes management, use of technology and potential complications, (Commissariat et al., 2020) our findings showed that parents desire to learn about and be involved in disease management.

In this study, parents relied more on personal sources of diabetes information than professional ones. While this may mean that parents prefer obtaining information from personal sources, it may also suggest that there is limited information provided by healthcare professionals. Previous studies have revealed that parents want to be educated directly by healthcare providers as opposed to websites or companies (Commissariat et al., 2020); therefore, it is necessary to diversify the educational contents provided by healthcare professionals.

Next, we examined the priorities in educational needs by topic among both patients and parents. We found that complication management was rated as the highest educational need by both groups. Given that the majority (89.6%) of our participants were as yet complication-naïve, this result suggests that patients and parents want to learn about the symptoms and preventive measures for complications despite not having developed complications yet. This is consistent with previous findings where patients with type 1 diabetes mellitus reported the highest educational need for complications (Park & Oh, 2014). In other words, patients' and parents' fear of potential complications is greater than their concern for present disease management. Considering that even patients with a high level of knowledge may still have high educational needs for complications (Park & Oh, 2014), it is possible that both educational needs for complications and fear of complications contributed to this result. Therefore, education programmes focusing on complications should include psychological support in addition to imparting knowledge.

By specific topics, in complication management, educational needs were the highest for symptoms and prevention of diabetic retinopathy (DR), followed by complication types, regular check-up, peripheral arterial complication and nephropathy. This suggests that despite being aware of the possibility of developing DR (Abdulaal et al., 2019), most patients and families still need education about specific symptoms and preventive measures. The global prevalence of DR is 36%–94%, and although it affects both T1DM and T2DM, it is more prevalent among patients with T1DM (Lee et al., 2015). Most cases are asymptomatic until the disease progresses to induce a loss of vision. However, early detection through screening and effective treatment can help prevent loss of vision (Lueder & Silverstein, 2005). Further, considering the high educational need for this topic, complications should be a priority educational topic for both patients and their families. In addition, as a previous study showed that awareness of DR is linked to undergoing annual eye examinations (Alswaina, 2021), comprehensive education about the symptoms, preventive measures and management of DR can help promote preventive behaviours.

In the complication management domain, the specific topics with high educational needs following DR were complication types and regular check-ups. Hence, teaching patients and their families about the less common types of complications and their

TABLE 3 Ranking of subitems of education needs ($N = 193$).

Categories	Subitems	T1DM patients ($n = 100$)		Parents of T1DM patients ($n = 93$)	
		Mean ± SD	Subitems ranking	Mean ± SD	Subitems ranking
Complication management		3.41 ± 0.67		3.61 ± 0.50	
	Retinopathy	3.45 ± 0.77	1	3.62 ± 0.53	1
	Complication types	3.43 ± 0.67	2	3.59 ± 0.59	7
	Regular check-up	3.43 ± 0.69	3	3.61 ± 0.51	2
	Peripheral arterial complication	3.42 ± 0.71	4	3.59 ± 0.56	5
	Nephropathy	3.40 ± 0.75	5	3.61 ± 0.53	3
	Cerebrovascular complications	3.39 ± 0.72	6	3.60 ± 0.55	4
	Neuropathy	3.38 ± 0.72	7	3.61 ± 0.53	3
	Heart complications	3.36 ± 0.73	8	3.59 ± 0.56	5
Characteristics of the disease		3.43 ± 0.54		3.51 ± 0.57	
	Diabetes management goals	3.48 ± 0.61	1	3.56 ± 0.58	1
	Pancreas and insulin function	3.44 ± 0.62	2	3.46 ± 0.65	3
	Diabetes progression	3.40 ± 0.68	3	3.55 ± 0.60	2
	Diabetes causes and symptoms	3.38 ± 0.65	4	3.45 ± 0.70	4
Physical activity and exercise		3.36 ± 0.64		3.53 ± 0.49	
	Exercise during complications	3.46 ± 0.67	1	3.55 ± 0.58	1
	Exercise method	3.40 ± 0.72	2	3.54 ± 0.54	2
	Type of exercise	3.36 ± 0.77	3	3.54 ± 0.54	2
	Importance of exercise	3.31 ± 0.73	4	3.51 ± 0.54	5
	Precautions during exercise	3.26 ± 0.79	5	3.54 ± 0.54	2
Continuous management		3.34 ± 0.58		3.56 ± 0.47	
	Latest trends	3.49 ± 0.64	1	3.68 ± 0.51	1
	Continuous blood glucose meter	3.42 ± 0.74	2	3.61 ± 0.49	2
	Sick day management	3.41 ± 0.59	3	3.58 ± 0.61	4
	Travel management	3.38 ± 0.66	4	3.49 ± 0.65	10
	Insurance	3.35 ± 0.87	5	3.58 ± 0.63	5
	Blood sugar management	3.34 ± 0.68	6	3.56 ± 0.60	7
	Vaccination	3.31 ± 0.75	7	3.45 ± 0.65	11
	Foot care	3.30 ± 0.76	8	3.58 ± 0.60	3
	Self-measurement of blood glucose, time and frequency	3.27 ± 0.83	9	3.51 ± 0.67	9
	Need for self-monitoring blood sugar	3.25 ± 0.83	10	3.53 ± 0.69	8
	Pancreas transplant	3.21 ± 0.90	11	3.56 ± 0.58	6
Medication		3.35 ± 0.57		3.49 ± 0.58	
	Blood sugar-affecting drugs	3.54 ± 0.61	1	3.66 ± 0.58	1
	Insulin dose adjustment	3.52 ± 0.64	2	3.54 ± 0.68	3
	Insulin side effects	3.46 ± 0.64	3	3.59 ± 0.61	2
	Insulin effects	3.44 ± 0.67	4	3.53 ± 0.65	4
	Insulin type and dosage	3.26 ± 0.75	5	3.46 ± 0.70	5
	Healthy food and folk remedies	2.89 ± 1.09	6	3.14 ± 0.82	6
Diet		3.27 ± 0.68		3.46 ± 0.53	
	Food management for complications	3.42 ± 0.73	1	3.49 ± 0.60	4
	Special day meal management	3.33 ± 0.80	2	3.42 ± 0.66	8
	Importance of diet	3.32 ± 0.72	3	3.52 ± 0.58	3

TABLE 3 (Continued)

Categories	Subitems	T1DM patients ($n=100$) Mean ± SD	T1DM patients ($n=100$) Subitems ranking	Parents of T1DM patients ($n=93$) Mean ± SD	Parents of T1DM patients ($n=93$) Subitems ranking
	Guidelines for eating out	3.31 ± 0.80	4	3.43 ± 0.61	7
	Amount of food	3.29 ± 0.76	5	3.44 ± 0.68	6
	Free food	3.27 ± 0.81	6	3.54 ± 0.56	1
	Glycaemic index	3.26 ± 0.82	7	3.54 ± 0.64	2
	Food ingredients list	3.23 ± 0.83	8	3.40 ± 0.68	9
	Restricted foods	3.17 ± 0.85	9	3.47 ± 0.58	5
	Food plan using food exchange table	3.12 ± 0.96	10	3.35 ± 0.72	2
Psychosocial needs		3.05 ± 0.73		3.38 ± 0.59	
	Social life	3.40 ± 0.82	1	3.62 ± 0.61	1
	Love and marriage	3.33 ± 0.83	2	3.58 ± 0.56	2
	Prejudice	3.30 ± 0.86	3	3.41 ± 0.74	7
	Pregnancy and childbirth	3.24 ± 0.82	4	3.45 ± 0.77	3
	Life with type 1 diabetes	3.21 ± 0.95	5	3.43 ± 0.74	4
	Peer relationships	3.09 ± 1.01	6	3.42 ± 0.66	5
	Parent–child conflict	2.88 ± 0.92	7	3.41 ± 0.66	6
	Puberty	2.86 ± 1.01	8	3.39 ± 0.82	8
	Early childhood growth and development	2.77 ± 1.00	9	3.13 ± 0.81	11
	Relationship with teachers	2.75 ± 1.06	10	3.17 ± 0.85	9
	Sibling conflict	2.69 ± 0.98	11	3.16 ± 0.86	10
Risk factors		3.09 ± 0.59		3.28 ± 0.58	
	Treatment of hyperglycaemia symptoms	3.42 ± 0.62	1	3.60 ± 0.61	1
	Stress management	3.41 ± 0.84	2	3.49 ± 0.65	3
	Treatment of hypoglycaemia symptoms	3.35 ± 0.63	3	3.56 ± 0.63	2
	Weight management diet	3.32 ± 0.76	4	3.33 ± 0.76	6
	Dyslipidaemia	3.18 ± 0.82	5	3.43 ± 0.67	4
	Hypertension	3.11 ± 0.82	6	3.38 ± 0.67	5
	Drinking	3.04 ± 0.94	7	3.04 ± 0.94	7
	Weight gain	2.50 ± 1.13	8	2.89 ± 1.08	8
	Smoking	2.50 ± 1.18	9	2.78 ± 1.07	9

Abbreviation: SD, standard deviation.

preventive measures, and the importance of regular check-ups, can help enhance their abilities to prevent complications and reduce fear.

Next, in the characteristics of the disease domain, the patients and parents reported the highest educational needs for diabetes management goals (blood glucose, blood pressure and cholesterol). This suggests that they have difficulty in setting goals for disease management, which supports previous findings that patients who are not provided diabetes-related education or continuous education have difficulty setting blood glucose targets and goals for diabetes management (Lange et al., 2014). In fact, management goals cannot be set by simply knowing the normal ranges of blood glucose, blood pressure and cholesterol, but require the ability to set step-wise goals in consideration of their current values, state and trends. Thus, it is important to provide pertinent education to enable patients and parents to set goals according to their condition.

In the physical activity and exercise domain, patients and parents had the highest educational needs for exercise during complications, followed by exercise method (frequency, duration and intensity). Exercise precautions in the presence of diabetic complications are related to the high educational needs for complication management, and this suggests that patients and parents had high educational needs for functional impairments caused by complications or special precautions related to complications. This result also highlights the importance of exercise frequency, duration and intensity and taking precautions specific to patients' disease and state.

In the continuous management domain, patients and parents had the highest educational needs for latest trends, followed by types and usefulness of continuous glucose monitors (CGMs). This

attests to the advances and increased interest in new technologies for diabetes management, such as islet cell transplantation, insulin and artificial pancreas. Previous studies also reported that advanced diabetes-related technology, such as CGMs and sensor augmented pump (SAP), are helpful in attenuating parents' fear of hypoglycaemia (Abitbol & Palmert, 2021). As shown here, new technologies instil hope for effective diabetes management, and patients require adequate information to use them effectively. Therefore, healthcare providers should continually update patients on latest developments in this area.

In the medication domain, the patients and parents had the highest educational needs for blood sugar-affecting drugs (including healthy foods and folk remedies), followed by insulin dose adjustment (e.g., insulin resistance, insulin sensitivity calculation). This demonstrates that patients and their families have high educational needs for drugs that affect blood glucose and drug interactions; and are highly interested in healthy foods or folk remedies. As hospitals do not readily provide information about healthy foods or folk remedies, patients are likely to obtain this information from different sources. Next, educational need for insulin dose adjustment was high because patients have to adjust their insulin dose on their own.

In the diet domain, patients and parents had the highest educational needs for food management for complications, which seems to be related to the high educational need for complication management. The topic ranked as the second-highest educational need in this domain was special day meal management (e.g., sick day, party), and this supports previous findings that patients must make careful plans for attending birthday parties or having a sleepover at a friend's or relative's house and that such events may be burdensome (Fritsch et al., 2015). The body's response to insulin differs when a person is sick; further, people consume various kinds of foods when eating out. Our results show that patients and their families find it difficult to deal with such special, non-routine situations.

In the psychosocial needs domain, patients and parents had the highest educational needs for social life, followed by love and marriage. This indicates that diabetes management can make engaging in peer and other social relationships challenging for patients. The next topic, 'prejudice', was ranked third among patients with T1DM but seventh among parents, showing that patients suffer more from prejudice related to diabetes. Prejudice may cause patients, who sometimes have to administer injections in public places, to be conscious of the negative public perceptions about needles and worry about how their actions may be perceived by others, which in turn may lead them to avoid engaging in their intended actions and instead engage in other unintended actions (Carlton et al., 2017). Such tendencies may manifest as stigma, criticism, negative social judgement, stereotyping, exclusion, rejection and discrimination (Browne et al., 2014). Our results are in line with a previous report that parents occasionally underestimate the negative emotions their children experience about their disease (Vervoort et al., 2007). The lower priority of this topic among parents in contrast to patients suggests that parents may fail to empathize or respond delicately to the challenges their children face. Thus, it is important to educate parents about how their child may be sensitive to diabetes-related prejudice.

Educational needs were the lowest for sibling conflict. As families of patients with a chronic disease, such as T1DM, are bound to face stressful situations, and this in turn may impact their family relationships, structure and coherence (Mellin et al., 2004), sibling conflict may occur due to the presence of a child with a chronic condition. In a study on healthy siblings of children with cancer, the healthy siblings were found to experience not only anxiety and fear about the treatment process but also depression and anger for their changed lifestyle, jealousy for the increased attention given to the sick child and consequent feelings of guilt, and a feeling of alienation for not being given attention and being unable to participate in the treatment process (Yu & Bang, 2017). While such challenges are expected among healthy siblings of children with T1DM, whether the reason for the low educational needs for sibling conflict is actually due to low conflict or is an indication that patients and parents are less sensitive to the psychosocial stress faced by healthy siblings warrants further research. Moreover, patients and parents should be educated about the possibility of conflict experienced by healthy siblings.

In the risk factors domain, patients and parents had the highest educational needs for treatment of hyperglycaemia symptoms, followed by stress management. This suggests that they contemplate the outcomes of a failed blood glucose control. In addition, high educational needs for stress management suggests that patients with T1DM and parents are in highly stressful situations, supporting the finding that parents of patients with T1DM suffer from continuous stress due to the complexity of chronic disease management and relentless infiltration of diabetes into daily life (Whittemore et al., 2012). Families of children with T1DM with lower socioeconomic status, families with an adolescent with T1DM and single-parent households with a child with T1DM were reported to have higher diabetes-related stress (Tsiouli et al., 2013). Thus, patients with T1DM and their parents need education about stress management and, particularly, factors that increase their vulnerability to stress should be identified to provide interventions accordingly.

In general, comprehensive education is given at the time of diagnosis. However, as studies have emphasized the need for repeated and individualized education for patients and their families (Commissariat et al., 2020), repeated customized interventions, as opposed to one-time education, are needed. In addition, considering previous studies from the school-based aspect, both teachers and parents evaluated that physical and human resources were insufficient, and it was necessary to raise awareness of the educational community about the needs of students with DM1 and to provide guidelines for emergency situations to teachers and staff at the centre (Armas Junco & Fernández-Hawrylak, 2022). Therefore, systematic education for parents, teachers and students must be provided.

4.1 | Limitations

This study analysed educational needs by educational topics, and therefore, the findings should be interpreted with caution, noting that the results do not indicate current education or knowledge level. The findings of this study also have limited generalizability.

4.2 | Recommendations for further research

We recommend that future studies investigate participants' level of knowledge and education as well and conduct qualitative studies on educational needs.

5 | CONCLUSIONS

This study examined the overall educational needs, including disease management and psychosocial aspects, among patients with T1DM and their parents and identified the differences in educational needs between patients and their parents. Based on our results, individualized education programmes that encompass both disease management and psychosocial aspects and prioritize contents with the highest educational needs should be developed and implemented for patients with T1DM and their families. The results of this study can serve as useful data for developing tailored educational and intervention programmes.

AUTHOR CONTRIBUTION

M.-K.C. and M.Y.K.; data curation, M.-K.C.; formal analysis, M.-K.C.; investigation, M.Y.K.; methodology, M.-K.C. and M.Y.K.; writing—M.-K.C. and M.Y.K. All authors read and agreed to the published version of the manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare that they have no competing interests.

ETHICS STATEMENT

In this study, all methods were performed in accordance with the relevant guidelines and regulations. The participants were informed about the research purpose, study procedure and rights of the participants and anonymity was guaranteed. In addition, only individuals who read the online consent form that included a description of the study and voluntarily consented to participate in the study were able to participate in the survey.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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