



Diabetes Education in Children and Adolescents with Type 1 Diabetes in China

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Abstract

Background: The prevalence of Type 1 Diabetes is increasing in pediatrics and diabetes education plays one of the most important role in the management of diabetes, especially in children. However, the related evidence concerned diabetes education is rare in children and adolescents. Therefore, we aimed to investigate the status of diabetes education in hospital, which could help us know the reality of diabetes education.

Methods: We choose a nurse who is mainly responsible for diabetes education and management in each hospital to fill out the questionnaire. Overall, 98 nurses were enrolled from tertiary children's specialized hospitals and pediatric wards of general tertiary hospitals from Jan 2018 to Dec 2019.

Results: Of 98 nurses enrolled, 61 (63.3%) nurses from 98 hospitals responded, 39 (63.9%) of them received specialized training in diabetes. There were no differences in education characteristics among regions of China. There were 26(42.6%) hospitals have a full-time nurse for diabetes education or nurses with endocrinology training increased with the number of cases/year ($P=0.02$ and $P=0.009$). The use of game-based education, knowledge assessment at discharge did not vary among hospital volumes, and the presence of a psychiatrist ($P=0.41$, $P=0.65$, and $P=0.85$, respectively). Diet management education is the most common (23.0%) difficulty in children diabetes education.

Conclusion: The level of diabetes education in children and adolescents varied among hospitals, but not among regions in China. There was a lack of resources provided for children and adolescents diabetes education in terms of training and specialized services.

Keywords: Children; Type 1 diabetes mellitus; Patient education; China

Introduction

More than 580,000 children and adolescents under the age of 15 in the world suffered from type 1 diabetes mellitus (T1DM), and the number of new patients each year is about 96,000. The prevalence of T1DM is 0.5% in the United States (1). In China, the incidence of T1DM is 1.01 per 100,000 person-years (2), China has more than

30,000 children between the ages of 1 and 14 with T1DM (3). And it became a serious threat to children's health and quality of life (4, 5).

T1DM is an endocrine disorder characterized by insulin deficiency usually due to autoimmune pancreatic β cell destruction, and resulting in hyperglycemia and complications such as ketoaci-



dosis, cardiovascular disease, nephropathy, and retinopathy (6-8). About 30% of children and adolescents present in diabetic ketoacidosis (DKA), a metabolic emergency (7,8). Chronic hyperglycemia can lead to multiorgan damage, resulting in renal, neurologic, cardiovascular, and other serious complications (7,8). T1DM patients requires their self-measurement of blood glucose levels and self-injection of multiple daily insulin injections or continuous subcutaneous insulin infusion (9-12). Hence, knowledge of T1DM is necessarily for them.

Diabetes education is the process of providing people with the knowledge and skills needed to complete diabetes self-management, manage crisis, and make lifestyle changes to successfully cope with the disease (6, 13) and many education programs are successful in improving diabetes control and quality of life of the patients (14, 15). Carrying out diabetes education and obtaining active cooperation from patients is a prerequisite for good control (6). As a chronic and lifelong disease, most treatments need to be done at home (9-12). Therefore, it is necessary to provide the patients, their parents, and schoolteachers the systematic professional health education program, including impart diabetes-related prevention and control knowledge, during the patients' hospitalization (9-12).

Chinese children's diabetes education started late (2, 16-18) and the number of children and adolescents with T1DM is relatively small. Therefore, manpower and material resources cannot be invested effectively. In order to learn more about the status of children and adolescents T1DM education in China, we investigated the situation of T1DM education in children and adolescents in 98 first-class tertiary hospitals in China.

Methods

Study design and participants

It was a survey study conducted in purposive sampling selected endocrine wards of tertiary children's specialized hospitals and pediatric wards of general tertiary hospitals. The question-

naire was filled out by nurses who are mainly responsible for diabetes education in their wards.

The survey was approved by all of the hospital management. Overall, 98 medical institutions across the country agreed to participate, 47 were endocrine wards of tertiary children's specialized hospitals, and 51 were pediatric wards of general tertiary hospitals. The institutional review board of our medical center approved this study (2020-IRB-043).

Survey tools

The self-designed "Questionnaire on the Current Situation of Children and Adolescents Diabetes Education" was developed and used. The questionnaire consists of general information on the hospital and the practice work of pediatric diabetes education. The questions about child diabetes education practice includes 25 items such as the subject educator, education object, education content, education form, education duration, affecting education quality, etc. The Cronbach's coefficient of the scale in this study was 0.78.

Survey method

From Jan 2018 to Dec 2019, researchers conduct unified online training for research objects. The training content included research purpose, interpretation of questionnaire content, matters needing attention when filling in the questionnaire. The training process lasted 1.5 h, and the researchers answered the questions raised by the research subjects. The members of the research team used the self-designed questionnaire to conduct a survey in the pediatric ward of the tertiary hospitals in the country. The questionnaire was filled out by the nurse responsible for diabetes education in each hospital.

Statistical analysis methods

The data was coded and double entered into a database. Continuous data were presented as means \pm standard deviation. Categorical data were presented as numbers and percentages. They were analyzed using the chi-square test or Fisher's exact test, as appropriate. SAS 9.4 (SAS Institute, Cary, NY, USA) was used for analysis.

P -values<0.05 were considered statistically significant.

Results

Participation and numbers of new cases/year

Overall, 61 valid questionnaires were retrieved. The questionnaire covered 40 cities in 21 prov-

inces across the country (37 of children's specialized hospitals and 24 were pediatric wards of general hospitals). Among these hospitals, the proportion of the number of patients with diabetes admitted annually, and the regional distribution of the number of patients admitted annually are shown in Table 1.

Table 1: Regional distribution of the numbers of hospitals and patients admitted annually

<i>Region</i>	<i>Hospitals N (%)</i>	<i>Number of chil- dren/year</i>	<i>N (%)</i>
Northeast	2 (2.3)	1-10	0
		11-30	1 (50.0)
		31-50	0
		51-100	0
		>100	1 (50.0)
North	3 (4.9)	1-10	0
		11-30	0
		31-50	0
		51-100	2 (66.7)
		>100	1 (33.3)
East	24 (39.3)	1-10	6 (25.0)
		11-30	3 (12.5)
		31-50	5 (20.8)
		51-100	5 (20.8)
		>100	5 (20.8)
Northwest	8 (13.1)	1-10	3 (37.5)
		11-30	2 (25.0)
		31-50	1 (12.5)
		51-100	1 (12.5)
		>100	1 (12.5)
Southwest	4 (6.6)	1-10	0
		11-30	1 (25.0)
		31-50	0
		51-100	2 (50.0)
		>100	1 (25)
Central South	20 (32.8)	1-10	6 (30.0)
		11-30	4 (20.0)
		31-50	3 (15.0)
		51-100	3 (15.0)
		>100	4 (20.0)

Contents, forms, and methods of education

All 61 pediatric medical institutions surveyed were carrying out diabetes education activities (100%), but only 32 had specific children and adolescents' diabetic clinics. Table 2 presents the methods of education. 48.3% educator were specialist nurses and 31.7% were doctors. Most edu-

cators received specialized training in diabetes (63.9%), followed by department training (52.5%), self-training (47.5%), and hospital training (34.4%). Both parents were targeted by the education (father: 80.3%; mother: 86.9%), as well as the child (70.5%). Out-hospitals follow-up groups were organized by 70.5% of the hospitals.

Table 2: Contents, forms, and methods of education

Variables	n (%)
Child diabetes clinic <i>Child diabetes educator</i>	32 (52.5)
Doctor	19 (31.1)
Primary nurse	8 (13.1)
Specialist nurse	29 (47.5)
Head nurse	4 (6.6)
Other	1 (1.6)
<i>Types of training received by educators (multiple choice)</i>	
Department training	32 (52.5)
Diabetes Specialist Nurse Training Course	39 (63.9)
Study abroad	6 (9.8)
Hospital training	21 (34.4)
Nurse self-study	29 (47.5)
Other	14 (23.0)
<i>Education object(multiple choice)</i>	
Mother	53 (86.9)
Father	49 (80.3)
Grandmother/grandfather	18 (29.5)
Child	43 (70.5)
Whole family	33 (54.1)
Out-of-hospital follow-up group	43 (70.5)
<i>Follow-up group manager(multiple choice)</i>	
Nurse	37 (60.7)
Doctor	36 (59.0)
Psychologist	7 (11.5)
Nutritionist	12 (19.7)
Patient's family	10 (16.4)

Characteristics of the education across regions

Among the hospitals, 26 (42.6%) had full-time diabetes education nurses, without significant difference among regions ($P=0.62$). Among hospitals, 90.2% of the nurses had training in endo-

crinology, also with no significant differences among regions ($P=0.06$). Only 85.3% of the hospital was evaluating the diabetes knowledge of the children and their parents at discharge. A few hospitals (21.3%) had full-time psychiatrists who can help the children and their family (Table 3).

Table 3: Characteristics of the education across regions

<i>Item</i>	<i>Hospital region</i>	<i>Yes</i>	<i>Total</i>	<i>P</i>
Full-time nurse engaged in diabetes education	East China	10 (41.7)	24	0.6240
	Central	10 (50.0)	20	
	South			
	Other areas	6	16	
	Total	26 (42.6)	61	
Train all nurses of endocrinology in children and adolescents' diabetes-related knowledge and skills	East China	21 (87.5)	24	0.0611
	Central	20	20	
	South	(100.0)		
	Other areas	14	17	
	Total	55 (90.2)	61	
Assess the knowledge of children and adolescents with diabetes and their parents at the time of discharge	East China	20 (83.3)	24	0.4605
	Central	18 (90.0)	20	
	South			
	Other areas	14	17	
	Total	52 (85.3)	61	
Full-time psychiatrist to psychologically intervene in children and adolescents with diabetes and their families	East China	3 (12.5)	24	0.1190
	Central	5 (25.0)	20	
	South			
	Other areas	5	17	
	Total	13 (21.3)	61	

Characteristics of education among hospitals with different volumes of T1DM patients

Table 4 shows the characteristics of education among hospitals with different volumes of T1DM patients. The proportion of hospitals with a full-time nurse for diabetes education increased from 6.7% in hospitals with 1-10 new cases per year to 61.5% in hospitals with >100 new cases

per year ($P=0.02$), no hospital has a diabetes educator who is fully engaged in the education and management of pediatric diabetes patients. More nurses offering diabetes education received endocrinology training in large-volume hospitals compared with the lower-volume hospitals ($P=0.009$).

Table 4: Characteristics of education among hospitals with different volumes of T1DM patients

<i>Item</i>	<i>Hospital scale (Patients/year)</i>	<i>Y</i>	<i>Total</i>	<i>P</i>
A full-time nurse engaged in diabetes education	1-10	1 (6.7)	15	0.016 9
	11-30	5 (45.5)	11	
	31-50	6 (46.2)	13	
	51-100	6 (66.7)	9	
	Over 100	8 (61.5)	13	
	Total	26 (42.6)	61	
Train all nurses of endocrinology in children and adolescents' diabetes-related knowledge and skills	1-10	10 (66.7)	15	0.009 4
	11-30	10 (90.9)	11	
	31-50	13 (100.0)	13	
	51-100	9 (100.0)	9	
	Over 100	13 (100.0)	13	
	Total	55 (90.2)	61	
Game-based teaching methods are applied in the development of childhood diabetes education	1-10	4 (26.7)	15	0.412 9
	11-30	3 (27.3)	11	
	31-50	7 (53.9)	13	
	51-100	4 (44.4)	9	
	Over 100	7 (53.9)	13	
	Total	25 (41.0)	61	
Assess the diabetes knowledge and skill of young patients and their parents when discharge	1-10	11 (73.3)	15	0.652 6
	11-30	10 (90.9)	11	
	31-50	11 (84.6)	13	
	51-100	8 (88.9)	9	
	Over 100	12 (92.3)	13	
	Total	52 (85.3)	61	
Full-time psychiatrist to psychologically intervene in children and adolescents with diabetes and their families	1-10	2 (13.3)	15	0.850 6
	11-30	2 (18.2)	11	
	31-50	3 (23.1)	13	
	51-100	2 (22.2)	9	
	Over 100	4 (30.8)	13	
	Total	13 (21.3)	61	

Difficulties of diabetes education

The last open question was "what do you think is the most difficult point in children and adolescents' diabetes education?" The answers were sorted into 1) diet management education (23.00%); 2) compliance of caregivers (19.7%); 3) compliance of the children (16.4%); 4) lack of specialized knowledge and ability of the medical staff (16.4%); and 5) imperfect social support for diabetes education (11.4%). The remaining 13.1% of the respondents did not express the difficulties of children and adolescents' diabetes education.

Discussion

Diabetes education is crucial to the proper management of patients with T1DM (6, 13), but the exact education status of children and adolescents with T1DM in China is poorly known. Therefore, this study aimed to examine the status of diabetes education of children and adolescents in China and to provide some effective reference for optimizing children and adolescents' diabetes education. The level of children and adolescent's diabetes education varies among hospitals with different numbers of new cases per year, but not among regions in China. There was a lack of resources provided for children and adolescents diabetes education in terms of training and specialized services.

The educator's level of practice directly determines the quality of education. The construction of specialized nursing teams plays a pivotal role in the development of specialized hospitals. It is the key to a team-based overall medical model (4). At present, despite a positive impact of diabetes education on outcomes in general (19), children and adolescents diabetes education in China lacks expert consensus or guidelines, and practitioners lack standardized training (16, 20). There is no independent institution in China to certify the qualifications of educators. Educators often choose relatively experienced medical staff in the treatment and care of children and adolescents with diabetes. Although 52.5% of the hospitals selected nurses to participate in the training

of diabetes specialist nurses, the training system is dominated by education and management of adult diabetes, and there is less knowledge and practical content related to children and adolescents' diabetes education (16, 20). The lack of professional training system or imperfect training systems for children and adolescents diabetes educators and the lack of professional qualifications for children and adolescents diabetes education practitioners have become a major factor hindering children and adolescents' diabetes education in China. Although a recent study reported differences in T1DM management in children and adolescents between Beijing and Shantou (one of the middle city in South China) (16), the present study does not reveal differences across all regions of China.

Due to the relatively low numbers of children and adolescents with T1DM, the investments in education resources are relatively low. Among the 61 hospitals surveyed, only 26 (42.6%) have full-time nurses respond for diabetes education, and no hospital has a diabetes educator fully engaged in the education and management of children and adolescents diabetes. Practitioners within medical institutions often not only educate patients with diabetes, but also perform other medical, teaching, or administrative tasks. Without sufficient time to do in-depth communication, exchanges, and individualized guidance with patients, it has also affected the quality of education. In a present study, 16% of the respondents considered that in the existing teams of children and adolescents' diabetes education, the knowledge of the education practitioners as not rich enough, and the lack of standardized training for education practitioners had become a problem for many practitioners in this field. Such barriers are not unique to China and have been observed in other countries (21).

Dietary guidance is crucial in children and adolescents' diabetes education, but the survey found that 65.6% of hospitals offered nutrition guidance through nurses. In the present study, 23.0% of the respondents considered that diabetic diet management is the most difficult part of children and adolescents' diabetes education because diet

guidance needs to involve relevant concepts and calculations. These nurses have acquired some knowledge of children and adolescents' diabetes nutrition through training or self-learning, but they are not trained nutritionists, resulting in inadequate knowledge. Implementing a multidisciplinary team is the key to the success of T1DM management (22, 23). For non-medical patients and caregivers, it is difficult to understand and master relevant knowledge only through one-time education knowledge guidance.

Only 11.5% of the hospitals in the survey cooperated with the psychiatry department to provide counseling to diabetic families. A follow-up survey of T1DM patients from onset to adulthood found that 42% of patients had at least one psychological problem, of which the most common were depression (26%), followed by anxiety (20%) and behavioral problems (16%) (24). Compared with healthy peers, the incidence of depression in T1DM adolescents and children is significantly increased, and mild to moderate depression is three times more frequent than that in the control group (25). T1DM adolescents and children have become a high-risk group of depression (26). The American Diabetes Association recommends that T1DM adolescents and children over 10 yr of age should be screened for depressive symptoms, and professional intervention should be taken in time to identify problems, regardless of the severity of the symptoms (27). Therefore, the education management of children and adolescents diabetes urgently requires the participation of professional psychotherapists and timely intervention.

About 20% of the respondents said that the compliance of caregivers and patients is the greatest difficulty of children and adolescents' diabetes education. Education is not only the spread of knowledge but also the internalization of theoretical knowledge into the behavior change of patients and caregivers, to make education meaningful. The lack of compliance directly affects the quality of education, and the quality of education directly affects the quality of life of patients. Furthermore, 11% of the respondents thought that the social support system, such as

the lack of the corresponding guarantee for the treatment conditions of children and adolescents with diabetes in schools, the failure of medical insurance to fully cover the treatment costs of children and adolescents with diabetes, and the lack or insufficient hospital investment in children and adolescents' diabetes education were major barriers to children and adolescents' diabetes education.

At present, there are a few training bases for diabetic education in China, but they are all for adults, and there are no training bases for children. Establishing a multidisciplinary diabetes education team to manage children and adolescents with T1DM in hospitals, homes, and schools with medication, diet, exercise, monitoring, and health education, and other aspects are important to control blood sugar, delay complications and improve quality of life (9-12). The family's main caregiver's, school teachers', or school nurses' participation in children and adolescents' education needs to be improved to ensure the safety of children and adolescents with T1DM. It is urgent to establish a multidisciplinary children and adolescent's diabetes education alliance to strengthen the sharing and communication of practical experience among educators, actively exploring the diabetes education practice models, and establishing a multidisciplinary education management training system, in order to promote the development of Chinese children and adolescents with T1DM. Since health education during hospitalization cannot meet the needs of patients, many diabetes education nurses in the world have begun to lead remote health education; it is also worth us learning (28).

Our study had some limitations. Firstly, only 98 hospitals were enrolled in this study, which was a small number of hospitals in China and the response rate of 63% was low, selection bias may exist. Secondly, the survey was self-designed and is not a validated questionnaire. The self-designed questionnaires may hinder the validity of this study and limit the reference for other researchers.

Conclusion

The level of children and adolescents diabetes education varies among hospitals with different numbers of new cases per year, but not significantly different among regions in China. There was a lack of resources provided for children and adolescents diabetes education in terms of training and specialized services.

Journalism Ethics considerations

Ethical issues (Including plagiarism, informed consent, misconduct, data fabrication and/or falsification, double publication and/or submission, redundancy, etc.) have been completely observed by the authors.

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Conflicts of interest

The authors declare that there is no conflict of interest.

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