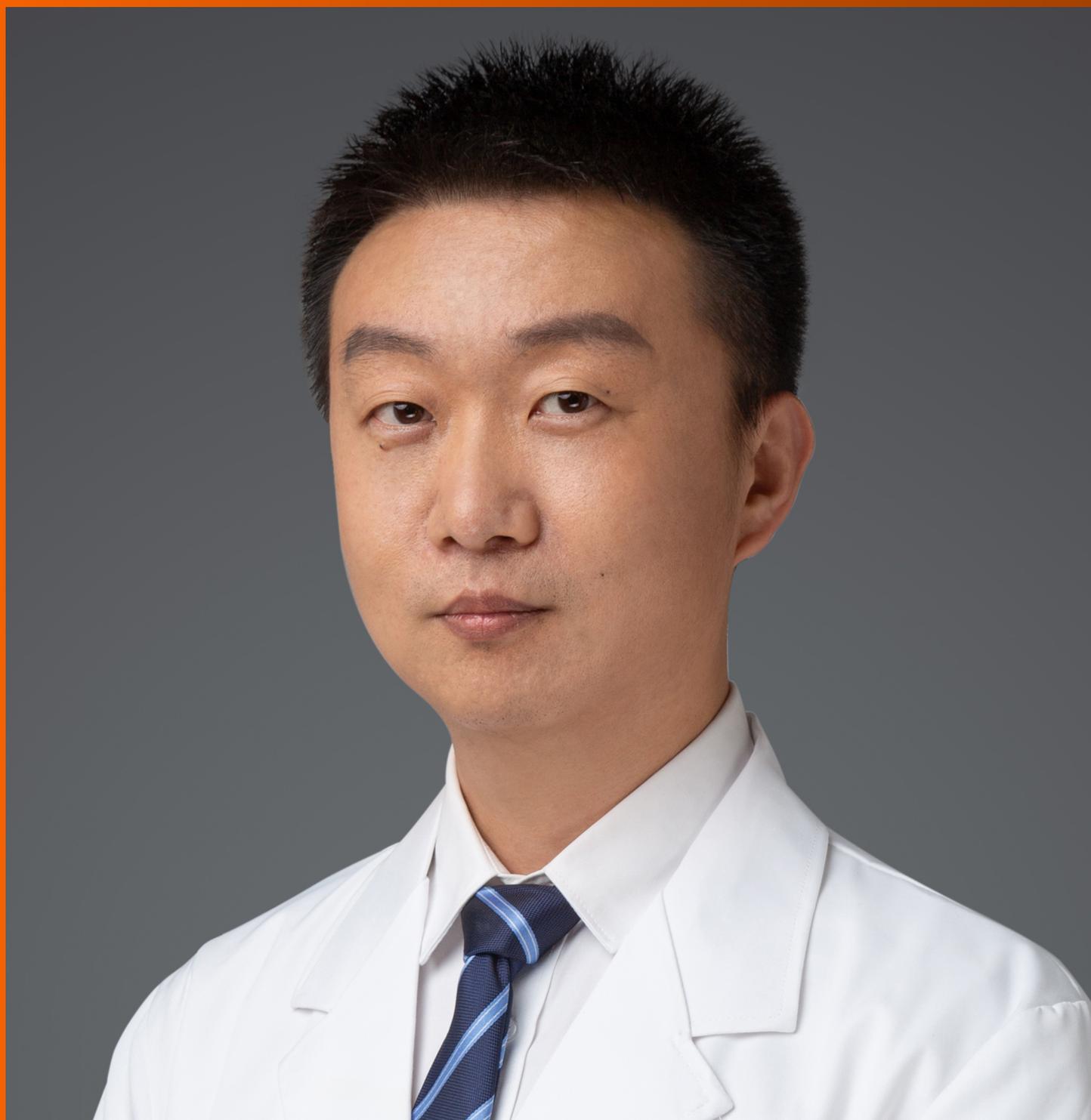


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**RESPONSIBLE EDITORS FOR THIS ISSUE**

Production Editor: Jia-Hui Li; Production Department Director: Yu-Jie Ma; Editorial Office Director: Jin-Lai Wang.

**NAME OF JOURNAL**

*World Journal of Clinical Cases*

**ISSN**

ISSN 2307-8960 (online)

**LAUNCH DATE**

April 16, 2013

**FREQUENCY**

Thrice Monthly

**EDITORS-IN-CHIEF**

Dennis A Bloomfield, Sandro Vento, Bao-Gan Peng

**EDITORIAL BOARD MEMBERS**

<https://www.wjnet.com/2307-8960/editorialboard.htm>

**PUBLICATION DATE**

April 16, 2021

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## Observational Study

# Parents' experience of caring for children with type 1 diabetes in mainland China: A qualitative study

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**Author contributions:** Tong HJ performed the study; Qiu F and Fan L analyzed the data; Tong HJ and Fan L wrote the manuscript.

**Institutional review board statement:** This study was conducted in accordance with the Declaration of Helsinki and was approved by the institutional review board of Shengjing Hospital, China Medical University, Shenyang, China (No. 2018PS362K). All participants provided written informed consent.

**Conflict-of-interest statement:** The authors declare no conflicts of interest in this study. No financial support was received for this study.

**Data sharing statement:** Statistical code and data are available from the corresponding author.

**STROBE statement:** The authors have read the STROBE Statement—checklist of items, and the manuscript was prepared and revised according to the STROBE Statement—checklist of items.

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## Abstract

### BACKGROUND

Parents of children with type 1 diabetes mellitus (T1DM) are under heavy caregiving stress, and parental caregivers' experience can affect the health outcomes of children with T1DM.

### AIM

To describe the true inner feelings of parents caring for children with T1DM.

### METHODS

Descriptive research methods were used to classify and summarize parents' experience when adapting to the role of caregivers for children with T1DM. The data was sorted and analyzed using content analysis. Themes of parents' experience caring for children with T1DM were refined, and their feelings were deeply investigated.

### RESULTS

A total of 4 themes and 12 subthemes were identified: (1) Desire for information (disease-related information, home care information, and channels of information acquisition); (2) Skill guidance needs (insulin injection techniques, skills required for symptom management, and skills for parent-child communication); (3) Seeking emotional support (family support, peer support from other parents of children with T1DM, and professional support); and (4) Lack of social support (needs for financial support and needs for social security).

### CONCLUSION

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**Manuscript source:** Unsolicited manuscript

**Specialty type:** Medicine, research and experimental

**Country/Territory of origin:** China

**Peer-review report's scientific quality classification**

Grade A (Excellent): 0  
Grade B (Very good): 0  
Grade C (Good): C  
Grade D (Fair): 0  
Grade E (Poor): 0

**Received:** August 13, 2020

**Peer-review started:** August 13, 2020

**First decision:** December 14, 2020

**Revised:** December 28, 2020

**Accepted:** January 27, 2021

**Article in press:** January 27, 2021

**Published online:** April 16, 2021

**P-Reviewer:** Theiss AL

**S-Editor:** Fan JR

**L-Editor:** Wang TQ

**P-Editor:** Li X



Exploring the true experience of parents caring for children with T1DM is of great significance for helping them adapt to their role as caregivers. Nurses should provide professional guidance in terms of information, skills, emotion, and social support to parental caregivers.

**Key Words:** Type 1 diabetes; Children; Parents; Care experience; Qualitative study; Family management

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**Core Tip:** Type 1 diabetes mellitus (T1DM) is a common chronic disease in children. Parents of children with T1DM are under heavy caregiving stress, and parental caregivers' experience can affect the health outcomes of children with T1DM. Descriptive research methods were used to classify and summarize parents' experience when adapting to the role of caregivers for children with T1DM. Exploring the true experience of parents caring for children with T1DM is of great significance for helping them adapt to their role as caregivers. Nurses should provide professional guidance in terms of information, skills, emotion, and social support to parental caregivers.

**Citation:** Tong HJ, Qiu F, Fan L. Parents' experience of caring for children with type 1 diabetes in mainland China: A qualitative study. *World J Clin Cases* 2021; 9(11): 2478-2486

**URL:** <https://www.wjgnet.com/2307-8960/full/v9/i11/2478.htm>

**DOI:** <https://dx.doi.org/10.12998/wjcc.v9.i11.2478>

## INTRODUCTION

Type 1 diabetes mellitus (T1DM) is one of the most common chronic diseases in childhood<sup>[1]</sup>, showing a doubled incidence in the past decade. However, the incidence varies across races, countries, and regions<sup>[2]</sup>. The incidence rate of T1DM among children in China is 5.6 per 100000<sup>[3]</sup>, which is lower than that of other countries. However, because of the large population in China, the number of T1DM patients currently ranks fourth in the world<sup>[4]</sup>, with the incidence rate increasing over the years.

Since the self-management of children with T1DM is a tedious and demanding care task<sup>[5,6]</sup>, it is extremely challenging for the parents and their children, who are at an important stage of physical and psychological development<sup>[7]</sup>. Parents of children with T1DM often feel isolated and helpless when faced with complex and long-lasting disease management. They have many needs in the process of adapting to the diagnosis and care of T1DM<sup>[8]</sup>. The parents of pediatric patients are troubled by various problems of managing the children's disease. This feeling persists throughout the complex daily management process. The parents continually worry about hypoglycemia and various T1DM emergency situations of their children<sup>[9-14]</sup>. Under the specific background of family, education, medical care, *etc.* in China, the parents' experiences of caring for their children with T1DM at different stages of the disease need to be discussed in depth to assist and support parents in adapting to their parental caregiver roles.

## MATERIALS AND METHODS

### Participants and methods

**Research design:** This study used descriptive qualitative research methods to describe the actual care experience of the patients in caring for children with T1DM. One-to-one and face-to-face semi-structured interviews were used to collect qualitative data, followed by content analysis to organize and to analyze the care experience and home care needs of the parents of children with T1DM.

**Research participants:** Parents of children with T1DM who were hospitalized in the pediatric endocrine ward of a tertiary hospital in Shenyang from January to November

2019 were selected as the research participants.

The inclusion criteria were: (1) Age  $\leq$  14 years; (2) Meeting the diagnostic criteria for T1DM, with a duration of disease more than half a year; (3) The parents were main caregivers; and (4) Being willing to participate in the study.

The exclusion criteria were: (1) Suffering from other chronic diseases; (2) At a critical stage; and (3) Parental caregivers cannot communicate in Mandarin.

### **Sampling methods and process**

Purposive sampling was selected, and the heterogeneity of sample selection was expanded in terms of parents' age, marital status, education level, and children's age and duration of disease. When the number of interviews reached 18, the data in our research was saturated, and no new information was obtained, so sampling was terminated.

### **Data collection**

The entire interview process was guided by a semi-structured interview outline to ensure that the content was conducted around the research purpose. The outline of the interview is based on the theory of individual and family self-management<sup>[15]</sup>. The duration of the interview lasted 45-60 min. The interview was recorded by one interviewer and one registrar after obtaining the consent of the interviewee. The outline of the interview is shown in [Table 1](#).

### **Data analysis**

The numbered recordings were transcribed verbatim into text documents within 48 h. Using content analysis method, with the assistance of NVivo 11.0 software, the text materials were sorted, coded, and summarized, and the topics were refined. Throughout the qualitative research process, the researchers respected the value of the research subjects, encoded the transcribed text with an open-minded attitude, and avoided preconceptions in evaluating the views and behavior of the research subjects.

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## **RESULTS**

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### **General information of research subjects**

A total of 18 parents of children with T1DM underwent one-to-one, semi-structured interviews. Among them, 12 were mothers, and 6 were fathers, with the age ranging from 32 to 48 years old. The children's disease course ranged from 8 to 43 mo, with 7 cases using an insulin pump and 11 cases using subcutaneous injections.

### **Experience of parents of children with T1DM**

By analyzing the text data, we extracted four themes from parents' experiences caring for children with diabetes: (1) Desire for information; (2) Skill guidance needs; (3) Seeking emotional support; and (4) Lack of social support. There are 12 subthemes within these four themes, which are shown in [Table 2](#).

#### **Desire for information**

The importance of the information was mentioned by all interviewees, with the desire for disease-related information, home care information (*e.g.*, diet, exercise, and rest), and expected reliable channels of information acquisition.

**Disease-related information:** In the early stage of diagnosis, most parents of children with T1DM were at an unfamiliar level because of their lack of understanding of the disease, therefore experiencing anxiety and uncertainty. For example, interviewee DM17 said, "I have heard of diabetes before, but I did not know that children could also get this disease. Once my child got diagnosed, I wanted to know the cause, the treatment, and curability of the disease."

**Home care information:** Interviewees reported that due to a lack of care information regarding the diet, exercise, and rest of the patients in the process of home care, less strict diet control and poor exercise compliance affected the blood glucose control of the patients. Diet was the main focus of the parents' attention and was also one of the most difficult factors for them to deal with. For example, interviewee DM7 said, "I really want the doctors and nurses to tell me what kind of food that my child can and cannot eat, in what amount, and how to prepare it, so I can write them all down in a

Table 1 Interview outline

Outline content	
1	Would you describe the initial disease conditions of your child and your reaction at the time?
2	Would you describe a day when you take care of your sick child?
3	Since your child was diagnosed with diabetes, what is the most difficult problem that you care about or encounter?
4	How do you think that your child's illness has affected your family life?
5	How do you manage your life in the process of taking care of your sick child?
6	As a caregiver, what are your needs in caring for your sick child?
7	How do you think about the role of caring for sick children?

Table 2 Themes and sub-themes of care needs

Theme	Sub-theme
Desire for information	Disease-related information
	Homecare information
	Channels of information acquisition
Skill guidance needs	Insulin injection techniques
	Skills required for symptom management
	Skills for monitoring blood glucose
	Skills for parent-child communication
Seeking emotional support	Family support
	Peer support from other parents of children with T1D
	Need for professional support
Lack of social support	Need for financial support
	Need for social security

little notebook. I have a hard time figuring out the calories of the diet. I wish I could ask the doctors and nurses to prepare a list of recipes so I can follow them; otherwise, it is too difficult for me to prepare the meals for my child”.

**Channels of information acquisition:** Parents of children with T1DM were eager to obtain more information about the treatment and care of their sick children and hoped that an information platform would be provided by professional medical staff. They were looking for all kinds of information on the Internet and worried about the lack of ability to screen and distinguish between right and wrong information. They hoped that the medical staff could provide a platform with as much correct information support as possible. For example, interviewee DM8 said, “Nowadays, we can find all kinds of information on the Internet, but there are always examples of falsehoods on the Internet. The more the information that I browse, the more I want to know, and I feel panicky deep down. I particularly hope that there will be a professional platform where I can ask question when I encounter problems that I cannot handle and receive timely answers from doctors and nurses”.

### **Skill guidance needs**

Most parents of the pediatric patients expressed the need for skills such as insulin injection techniques, symptom management, blood glucose monitoring, and parent-child communication skills. They hoped to receive help and guidance from nurses on these skills.

Interviewee DM17 said, “I was confused at the beginning and did not know where to start. Children who had used an insulin pump in the hospital would need insulin injection after being discharged. Although the nurse taught me the way, I was afraid to do it. They should have let me try at least twice before my child was discharged. When

we got home, I still did not dare to do it by myself. I had never practiced insulin injection before. It would be great if the parents were asked to perform the last insulin injection while in the hospital when you make an appointment for hospital discharge because I still remember how my hands trembled when I injected my child the first time, causing me to inject too much insulin”.

Because of the needs for daily care, parents are more involved in the daily life, such as diet and exercise. However, when children grow up and increase their autonomy, the transition from parent management to self-management often triggers parent-child conflicts because of factors such as different concerns about diabetes between the parents and children, affecting the parent-child relationship. Most parents of the pediatric patients indicated that they needed to learn the skills for parent-child communication.

Interviewee DM16 said, “Now I really do not know what the child is thinking. She gets agitated easily if she does not like what I say. She thinks that I am nagging and asking too many questions. I am a little afraid of interacting with my child. People say that a bad mood will affect the blood glucose level. After raising my child for so many years, I do not know how to communicate with her”.

### **Seeking emotional support**

Parents play an important role in the management of children with T1DM and are also under tremendous psychological stress<sup>[16,17]</sup>. The caregivers of children with T1DM hoped to receive more emotional support from families, societies, and professionals.

**Family support:** Family support refers to the material, emotional, and information assistance provided by family members. Because T1DM is a lifelong disease, parents with sick children consider that their children’s illness will affect their future employment, marriage, and other aspects of their lives and, therefore, hide the information about their children’s illness to avoid discrimination<sup>[18]</sup>. Parents of children with T1DM are unwilling to tell people about their children’s illness. Therefore, the emotional support for the parents of children with T1DM is expected to come from their spouses and other family members. Through good emotional support between the spouses, they can adjust their psychological state and better adapt to the role of caregiver of the pediatric patients. For example, interviewee DM4 said, “Perhaps all couples are like this. Everyone has different expectations for their children. In my opinion, the healthy growth of my child is the most important, and my wife believes that good education is the most important thing for my child. We have different expectations and goals. I feel aggrieved when my wife does not understand me when I discipline our child. Rather than other people, I really hope to get understanding and support from my closest family members.”

**Peer support from other parents of children with T1DM:** The parents of children with T1DM said that they would like to have more understanding and peer support from other parents of children with T1DM and were keen to join a peer support group to get emotional communication and seek empirical support. They believed that peers who had experienced similar diseases or physical conditions could help each other in practical, social, and emotional aspects. Given the common experiences, they were prone to empathy. Hence, peer support may meet the emotional needs of the parents. These patients who had the same caring experience would also help each other and share information on disease management.

Interviewee DM14 said, “There are still many people with diabetes. We are the jellybean families and have sugar babies. We are all somehow suffering from the disease and can communicate with and encourage each other. Some peers are patients and their families whom we met during the hospitalization. If we have questions, we can get answers from the peer group based on others’ experiences. We support and encourage each other and sometimes meet and hang out to build the relationship.”

**Professional support:** In the interviews, the parents of children with T1D indicated that they had strong desire to get emotional support from the medical staff and believed that the authoritative language of professionals was positive and comforting, helping improve the compliance of the children and their families. For example, interviewee DM13 said, “The nurses told us some stories about other diabetic patients to cheer us up. Sometimes, it is hard for us to ask our child to listen and follow what we say. Only the words of professional doctors and nurses convinced my son.”

### **Lack of social support**

The current family structure in China is dominated by typical nuclear families, and

after the child becomes ill, it has a serious impact on the family of the sick child. Most parents with sick children said that they needed financial support and social security.

**Need for financial support:** Since T1DM is a chronic disease, children with T1DM need to rely on insulin therapy for the rest of their lives<sup>[19]</sup>. Because of the sustained disease course and the uncertainty of the disease outcome, the families of children with T1DM are under great financial stress. Many families have changed their career plans so to take care of their children, thereby reducing their financial resources. They bear enormous financial burdens. Given the heavy financial burden, medical insurance is needed in these families to relieve the financial stress. For example, interviewee DM1 said, “The greatest challenge of our family is our finances. We need money for the medications and follow-ups of our sick child. I have to quit my job to take care of my child and rely on my husband to earn a living for the entire family. We have a huge financial burden. We mostly hope to get some financial assistance.”

**Need for social security:** Social security refers to medical security and social support resources. Currently, the lack of social support is mainly reflected in the lack of social support medical resources and support systems in China, especially for children who reach school age and leave home to study at school, which brings challenges to disease management.

Interviewee DM9 said, “I specifically hope that the economy of China will become more developed, and the medical insurance policy will become more and more complete, so I will be able to be reimbursed for all medications that my child needs. It will be the greatest blessing for families with diabetic patients like us.”

For school-age children, due to the national conditions of China, schools do not have nurses who are responsible for diabetes management, and parents of children with T1DM urgently need the formation of relevant auxiliary support networks. For example, interviewee DM13 said, “Since my child has started going to school, my heart really trembles as soon as the school calls, and I am afraid that my child will have an accident. Teachers at school do not know how to take care of diabetic children, and the schools generally have no nurse specialist. I am really afraid that there will be an accident.”

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## DISCUSSION

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T1DM requires lifelong treatment and management, and many parents of children with T1DM are under physical and psychological stress. They are also under a tremendous financial burden and urgently need emotional and social security support.

### ***Improving the content of health education to meet the information needs of parents of children with T1DM***

Parents with T1DM children need to learn more about disease-related information, homecare information (e.g., diet, exercise, and rest), and channels for information acquisition. Because children and adolescents are in a period of physical and mental growth, this makes the process of diabetes management more complicated in these populations<sup>[20]</sup>. To ensure the normal growth and development of the children, children with T1DM and their families should receive information about insulin injection, insulin dose adjustment, diet adjustment, exercise, blood glucose monitoring, and prevention of and responses to hypoglycemia. The results of our interviews showed that the parents of children with T1DM lacked information about the disease treatment, and their ability to manage their children’s diet was poor. They were unable to allocate diets reasonably and were at a loss in the calculation of carbohydrates. Therefore, many children with T1DM had poor blood sugar control<sup>[21]</sup>. Therefore, to meet the needs for information acquisition, it is recommended to form a knowledge domain module based on the information needs of the parents of children with T1DM and to implement appropriate education in the hospital and telephone guidance for the caregivers after the patient’s discharge.

### ***Adopting appropriate strategies to strengthen skills training for parents of children with T1DM***

From the beginning of the treatment of children with T1DM, the family members need to acquire relevant skills to care for the children, such as skills for monitoring blood glucose, skills for applications of insulin pens or pumps, knowledge of insulin injection sites and injection techniques, and diabetes self-management daily writing

(writing content and frequency of writing). Similar to a previous study<sup>[22]</sup>, we found that, due to the emotional stress of the parents of children with T1DM at the early stage of diagnosis, it is difficult for them to acquire a large number of disease-related skills in a short period of time, which makes it challenging to provide homecare after the children are discharged. Thus, it is necessary to set an appropriate time point based on the education level and skill training needs of the parents of children with T1DM to complete the skill training in a planned way before the children are discharged from the hospital.

### **Parents of children with T1DM require emotional support from families, peer groups, and professionals**

Our results showed that the parents of children with T1DM hoped to get more support from their families, peers (other parents of children with T1DM), and professionals. Because of the child's illness, both parents and their family members need to participate in the daily care of the child so that the physical and mental burden of the main caregiver can be eased. Furthermore, the experience support of patient support groups plays an important role in reducing the psychological stress of the families of children with T1DM. The caregivers of the children expected professionals to hold symposiums for the families to improve their understanding, share their experiences, and provide mutual support in addition to the WeChat group exchange and the diabetes summer camp. They also hoped to get information and emotional support from medical staff and to establish effective channels for communication and consultation.

### **The social support system should be improved to meet the social support needs of the parents of children with T1DM**

With the reform of the medical security system, China has initially constructed a multi-level medical security system and achieved a historic change in the medical security system, providing financial security for families with sick children. However, given the reimbursement ratio of insulin pumps or pens used by children with T1DM and many of the children involved in reimbursement from other regions, the financial burden caused by the disease treatment of the children still exists. For school-age children, diabetes management at school has an important impact on their blood glucose control<sup>[23]</sup>. We should gradually carry out training for relevant school personnel and other people who come in contact with the sick children and eventually form a social support network for children with T1DM.

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## **CONCLUSION**

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The parents' care experience further verifies their needs as caregivers. The care experience of parents of children with T1DM is staged and individualized. Nurses should provide professional guidance in different stages and in a planned way, which can help parents of children with T1DM adapt to the roles of their caregivers.

## **ARTICLE HIGHLIGHTS**

### **Research background**

Type 1 diabetes (T1DM) is one of the most common chronic diseases in childhood. Since the self-management of children with T1DM is a tedious and demanding care task, it is extremely challenging for the parents and their children. Parents of children with T1DM are troubled by various needs of the child's diabetes management. Under the specific background of family, education, medical care, *etc.* in China, the parents' experience of caring for their children with T1DM at different stages of the disease need to be discussed in depth to assist and support parents in adapting to their parental caregiver roles.

### **Research motivation**

As a lifelong disease, the disease management of T1DM is long-term and arduous. Children's families, especially their parents, are the main caregivers of children. It is necessary to explore the physical and psychological needs of parents of children with T1DM after diagnosis and the changes of their needs in different stages of care, so as to

assist and support parents to adapt to their role changes and improve the quality of care of children with T1DM.

### Research objectives

This research aimed to describe the real inner feelings and care experience of parents in the process of caring for children with T1DM, and to explore the categories and themes of care needs of parents of children with T1DM.

### Research methods

Descriptive research methods were used to classify and summarize parents' experience when adapting to the role of caregivers for children with T1DM. The data was sorted and analyzed using content analysis. Themes of parents' experience caring for children with T1DM were refined, and their feelings were deeply investigated.

### Research results

A total of 4 themes and 12 subthemes were identified: Desire for information, skill guidance needs, seeking emotional support, and lack of social support.

### Research conclusions

Exploring the true experience of parents caring for children with T1DM is of great significance for helping them adapt to their role as caregivers. Nurses should provide professional guidance in terms of information, skills, emotion, and social support to parental caregivers.

### Research perspectives

The care experience of parents of children with T1DM is staged and individualized. Nurses should provide professional guidance in different stages and in a planned way, which can help parents with T1DM adapt to the roles of their caregivers.

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