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## Characterizing Common Challenges Faced by Parental Caregivers of Children with Type 1 Diabetes Mellitus in Mainland China: A qualitative study

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3 **Characterizing Common Challenges Faced by Parental Caregivers of Children**  
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5 **with Type 1 Diabetes Mellitus in Mainland China: A qualitative study**  
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3 **1 Abstract**  
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5 **2 Objectives:** Parental caregiver psychology affects outcomes of children with Type 1  
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8 **3 Diabetes Mellitus (T1DM).** This study aimed to qualitatively examine perceptions of  
9  
10 **4 common challenges among parental caregivers of children with T1DM (T1DM Parental**  
11  
12 **5 Caregivers).**

13  
14 **6 Setting:** 45-60 minutes semi-structured interviews were conducted with T1DM  
15  
16  
17 **7 Parental Caregivers.** Interview recordings were transcribed and coded in NVivo 11.0 to  
18  
19 **8 observe emergent themes.**

20  
21 **9 Participants:** Eligible T1DM Caregiving Parents (parent(s) and/or legal guardian(s))  
22  
23  
24 **10 were identified from caregivers attending visits with children hospitalized or assessed**  
25  
26 **11 in the Pediatric Neuroendocrinology Department of Shengjing Hospital, China Medical**  
27  
28 **12 University in Shenyang from January 2018 to June 2019.**

29  
30 **13 Primary and secondary outcome measures:** Not applicable.

31  
32 **14 Results:** Content analysis revealed 5 common themes with 14 subthemes, including  
33  
34 **15 persistent psychological stress (catastrophic emotions, emotional distress, and altered**  
35  
36 **16 self-efficacy), family function change (altered family life patterns and changes in**  
37  
38 **17 parental role/function), challenges in daily management (technical challenges,**  
39  
40 **18 emotional regulation, parent-child conflict, and transition of care autonomy from parent**  
41  
42 **19 to child), financial burden (cost burden of treatment and altered family economics), and**  
43  
44 **20 lack of social support (social activity limitations and insufficient support systems). All**  
45  
46 **21 were highly saturated across interview data.**

47  
48 **22 Conclusions:** Young children with T1DM rely on parental caregivers for disease  
49  
50  
51 **23 management and to one day become capable of autonomous self-management as they**  
52  
53  
54 **24 age. However, both the period of emotional disturbance during initial diagnosis,**  
55  
56 **25 psychological stresses of long-term caregiving, and conflict emerging from transition**  
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3 26 for parental to child responsibility for care can cause psychological effects detrimental  
4  
5 27 to parental caregivers and T1DM children. This work provides compelling evidence for  
6  
7 28 the role of assessment and intervention in parental caregiver psychological and  
8  
9 29 emotional wellbeing in diabetes care, as well as the need for improved social and school  
10  
11 30 support for children with T1DM in China.

12  
13  
14 31 **Keywords:** Type 1 Diabetes Mellitus, Grounded Theory, Qualitative Methods,  
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16 32 Caregiving, Diabetes Care, Psychological Perceptions  
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19 33

20  
21 34 **Strengths and limitations of this study**

- 22  
23  
24 35 1. This is the first study, which described the real condition of young children with  
25  
26 36 T1DM rely on parental caregivers for disease management in China.  
27  
28 37 2. This study demonstrate that both the period of emotional disturbance during initial  
29  
30 38 diagnosis, psychological stresses of long-term caregiving, and conflict emerging from  
31  
32 39 transition for parental to child responsibility for care can cause psychological effects  
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34 40 detrimental to parental caregivers and T1DM children.  
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36 41 3. This study provides compelling evidence for the role of assessment and  
37  
38 42 intervention in parental caregiver psychological and emotional wellbeing in diabetes  
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40 43 care.  
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42 44 4. This study is limited by the interpretation of the reviewers and coders.  
43  
44 45 5. This is a single-center study, which limited the generalizability of the findings of  
45  
46 46 this study and a further multicenter study was needed.  
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## 48 **Background**

49 Type 1 Diabetes Mellitus (T1DM) is a common chronic disease in children, in which  
50 the parental caregiver and child diagnosed with T1DM must take on management tasks  
51 associated with the disease, with financial, emotional, and social impact on the family  
52 unit<sup>1</sup>. An increasing number of families with young children are impacted by T1DM,  
53 with the incidence of T1DM increasing by as much as 2% to 5% each year worldwide<sup>2</sup>.  
54 In China, the incidence of T1DM in children is currently 5.6 per 100,000 live births<sup>3</sup>.  
55 Although the incidence of T1DM in China is lower than that in Europe or the United  
56 States, China ranks fourth among countries for T1DM occurrence—and the number of  
57 cases is increasing each year<sup>4</sup>. However, communities in China generally have less  
58 resources and fewer T1DM cases outside of urban centers, which can increase the strain  
59 on Chinese parental caregivers. Thus, examining the situation of middle- and low-  
60 income parents of children with T1DM in China is essential to improving resources for  
61 T1DM care and long-term outcomes.

62 Management of T1DM in children involves changes in daily living activities that affect  
63 not only the child receiving care but also the caregiver, including responsibility to  
64 ensure continuous glucose monitoring (4 or more times per day) and insulin injection  
65 using an insulin pump or injecting insulin multiple times a day, as well as tracking and  
66 calculating daily carbohydrate intake and physical activity levels important to  
67 prevention of hypoglycemic and hyperglycemic episodes<sup>5,6</sup>. Children with T1DM  
68 under age 13 are unable to self-manage their T1DM care, and instead rely heavily on  
69 their parental caregiver for disease management<sup>7</sup>. Treatment for children with T1DM is  
70 aimed at ensuring stable blood glucose levels, minimizing occurrence of potentially  
71 deadly hypoglycemic events, and preventing long-term complications of diabetes as the  
72 child grows<sup>8</sup>. These responsibilities place immense psychological financial stress on

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2  
3 73 parental caregivers.  
4

5 74 Owing to the relatively lower incidence of T1DM outside of urban centers in China,  
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8 75 the emotional toll, financial burden, and social isolation experienced by parental  
9  
10 76 caregivers of young children with T1DM can be immense. Despite improvements in  
11  
12 77 T1DM medications and treatment technologies, many children in child still experience  
13  
14 78 adverse health effects due to blood glucose control<sup>9</sup>. Recent research suggests that,  
15  
16 79 more than 58.6% of children with T1DM in China do not achieve sustained hemoglobin  
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18 80 control (glycosylated hemoglobin lower than 7.5%)<sup>10</sup>. This can lead to complications  
19  
20 81 caused by poor blood glucose control that have adverse impact on the child's growth  
21  
22 82 and long-term health, and place significant burden on caregivers and the family unit.  
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25 83 Thus, there is a need to study T1DM care, and its impact on parental caregivers, through  
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27  
28 84 a social lens.  
29

30  
31 85 Rankin et al. (2018)<sup>1</sup> used qualitative methods to examine the strategies and motivations  
32  
33 86 of children with T1DM and their caregivers, providing insights into how diabetes  
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35 87 management can be improved. Researchers have also demonstrated that successful  
36  
37 88 disease management of children with T1DM not only requires the children to manage  
38  
39 89 their individual health, but also requires their cooperation with caregivers who share  
40  
41 90 the responsibility for the child's medical management<sup>11</sup>. These burdens can, however,  
42  
43 91 result in caregiving parents of children with T1DM feeling isolated and helpless when  
44  
45 92 faced with the challenges of chronic disease management. Psychologically, parents man  
46  
47 93 manifest a sense of self-doubt, guilt, or anxiety, and many experience traumatic initial  
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49 94 confusion as they try to integrate these new responsibilities into their family's routine  
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51 95 when their child is first diagnosed<sup>12</sup>. These feelings may be transient or persist, and may  
52  
53 96 be exacerbated if a child experiences hypoglycemic events or other emergency  
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55 97 situations that contributes to caregiver trauma and anxiety<sup>13-15</sup>. Understanding the  
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3 98 experiences of parental caregivers of children with T1DM is of great significance in  
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5 99 improving clinical and social interventions to help parents adapt to the role of caregiver,  
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8 100 and achieve optimal health outcomes for their children. However, current research on  
9  
10 101 children with T1DM in China is primarily limited to quantitative studies on the quality  
11  
12 102 of life (QoL) of children<sup>15</sup>, psychological state<sup>16</sup> and coping style of the children or their  
13  
14 103 parents<sup>17</sup>.

15  
16  
17 104 Qualitative research methodologies can provide actionable insights into the  
18  
19 105 psychological state, behaviors, and motivations of patients and caregivers managing  
20  
21 106 T1DM<sup>1</sup>. This socio-ethnographic study employs qualitative methods to examine the  
22  
23 107 perceptions of parental caregivers of young children (aged 14 or younger) with T1DM  
24  
25 108 in China, providing insights into the key challenges as caregivers transition from  
26  
27 109 complete management of young children with T1DM to an older child with increasing  
28  
29 110 autonomy over his or her medical care. Thus, this research is designed to provide  
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31 111 actionable insights for improving social support and management of these patients, in  
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33 112 a holistic context that considers the parental caregiver and family unit  
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36

### 37 **Methods**

#### 38 **Study Population and Design**

39  
40 114 Qualitative research methods were employed to examine social, emotional, and  
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42 115 experiential perceptions of parent(s) and/or legal guardian(s) with children diagnosed  
43  
44 116 with T1DM, referred to as T1DM Caregiving Parent for purposes of this article.  
45  
46 117 Synchronous, in-person, semi-structured interviews were conducted to collect  
47  
48 118 qualitative data, and emergent heuristic content analysis was subsequently performed  
49  
50 119 on transcripts. Eligible T1DM Caregiving Parents were identified from caregivers  
51  
52 120 attending visits with children hospitalized or assessed in the Pediatric  
53  
54 121 Neuroendocrinology Department of Shengjing Hospital, China Medical University in  
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3 123 Shenyang from January 2018 to June 2019.  
4

5 124 To be eligible for participation in study interview, T1DM Caregiving Parents were  
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7 125 required to (1) be the parent and/or legal guardian of a child 14 years of age or younger  
8  
9 126 with diagnosed T1DM, and (2) be a primary caregiver during at least 6 months of  
10  
11 127 continuous care for child being treated for T1DM during this period<sup>18</sup> T1DM  
12  
13 128 Caregiving Parents were considered ineligible to participate in interviews if (1) the  
14  
15 129 child with T1DM also experienced other significant comorbidities or chronic diseases;  
16  
17 130 (2) the child with T1DM was considered to required immediate medical care or  
18  
19 131 treatment where the study could pose an undue burden on the patient or caregiver; (3)  
20  
21 132 T1DM Caregiving Parent was unable to communication fluently in the local language  
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23 133 of the investigator (Mandarin Chinese).  
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28 134 This study was conducted in accordance with the Declaration of Helsinki and was  
29  
30 135 approved by the Institutional Review Board (IRB) of Shengjing Hospital, China  
31  
32 136 Medical University, Shenyang, China (Approval no. 2018PS362K). All participants  
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34 137 provided written informed consent prior to participating in interviews.  
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### 37 138 **Sampling Methods and Process**

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40 139 Purposive nonprobability sampling was used, in which eligible T1DM Caregiving  
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42 140 Parents were approached for participation as they presented in clinic. To ensure a  
43  
44 141 representative sample, the heterogeneity of sample selection was expanded for T1DM  
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46 142 Caregiving Parent age, marital status, education level, and T1DM child age and disease  
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48 143 course. The study was discontinued when qualitative data reached saturation, which  
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50 144 was expected to occur between 15 and 20 interviews, as previously described<sup>19,20</sup> When  
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52 145 the number of interviews reached 20, the data in our research was saturated, and no new  
53  
54 146 information was obtained, so sampling was terminated.  
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### 58 147 **Data Collection**

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3 148 An IRB-approved semi-structured interview outline was used to ensure consistency  
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5 149 while performing interviews. The interview structure was based on the theory of  
6  
7 150 individual and family self-management<sup>21</sup>, and formulated through expert evaluation of  
8  
9 151 the research purpose, population, and existent body of literature. The outline used in  
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11 152 interviews is shown in **Table 1**. The planned duration of the interview was 45 to 60  
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13 153 minutes.

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16  
17 154 Upon arrival at the clinical site, the head nurse of the clinical unit familiar with the  
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19 155 T1DM Caregiving Parent met the interviewee, led the interviewee to the interview site,  
20  
21 156 and made introductions with the interviewer. Prior to the start of the interview, the  
22  
23 157 interviewer explained the purpose, significance, methods, rights of the interviewee, and  
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25 158 privacy protection measures. Written informed consent was then obtained before  
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27 159 starting each interview.

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31 160 The interview location was selected as audio visual classroom located in the Pediatric  
32  
33 161 Neuroendocrinology Ward. This location was selected for the quiet environment, free  
34  
35 162 of distractions. Interviews were conducted by the authors, who were provided with  
36  
37 163 training on semi-structured interviews and use of neutral, objective, and non-leading  
38  
39 164 language during the interview to maximize data integrity.

#### 40 41 42 165 **Data Transcription and Coding**

43  
44  
45 166 Each interview was recorded using audio recording devices, and digitally transcribed  
46  
47 167 asynchronously (with 48 hours after each interview) by the researchers. Transcripts  
48  
49 168 were recorded in MS Word (Microsoft, USA), and verified by a second researcher. To  
50  
51 169 ensure data integrity, interviewees were provided a copy of their interview transcript  
52  
53 170 and allowed to suggest corrections, which, where appropriate, were assessed and  
54  
55 171 integrated by the researchers upon review of the original recording.

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57  
58 172 Heuristic coding was performed using emergent grounded theory methods<sup>20</sup> manually  
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3 173 using transcripts imported into NVivo 11.0 (QSR International, USA) using sort,  
4  
5 174 manual code, summarize text data, and identify and refine themes. Coding was verified  
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8 175 by a second researcher, the numbers were used to identify the interviewees in place of  
9  
10 176 their real names, DM1-DM20. Emergent themes and subthemes were identified using  
11  
12 177 a grounded theory approach.

### 14 178 **Data Analysis and Reporting**

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16  
17 179 Textual coding results in NVivo 11.0 (QSR International) were reported as counts and  
18  
19 180 percentages (data not shown) and themes/sub-themes were presented descriptively  
20  
21 181 using qualitative analysis methods. All analyses were performed in the local language  
22  
23 182 of the interview conduct (Mandarin Chinese), and the data were analyzed and collected  
24  
25 183 simultaneously. The theme of the interviews was extracted using content analysis  
26  
27 184 methodology by way of three-grade coding. Final results were translated to English to  
28  
29 185 broader access to these results. All translations were performed by the researchers to  
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31 186 ensure integrity of translations.

### 32 187 **Results**

#### 33 188 **Participant Characteristics**

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38 189 Saturation was reached when 20 T1DM Caregiving Parents (N = 20) completed  
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40 190 interviews. Interviewed T1DM Caregiving Parents were aged 30 to 53 years of age  
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42 191 (10.6±2.45), including 7 fathers and 13 mothers (gender roles were self-identified by  
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44 192 the interviewee). Of these patients, 8 were caregivers of children with T1DM that were  
45  
46 193 treated with islet pumps, and 12 were caregivers of children with T1DM that were  
47  
48 194 treated with subcutaneous injections. Socio-demographic information for T1DM  
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50 195 Caregiving Parents completing interviews and demographic and clinical condition of  
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52 196 their children are summarized in **Table 2**.

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58 197 By analyzing the transcripts of interviews, five emergent themes were observed  
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3 198 consistently throughout the interview data: (1) persistent psychological stress; (2)  
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5 199 family function changes; (3) challenges in daily management; (4) excessive economic  
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7 200 burden; (5) lack of support system. Further, 14 subthemes within these 5 themes,  
8  
9 201 summarized in **Table 3**. The themes/sub-themes are further characterized below.

## 202 **Theme of Persistent Psychological Stress**

203 Persistent psychological stress was identified as prominent theme across interviews,  
204 with four key sub-themes emerging from coding:

### 205 **(1) Catastrophic Emotional Experience**

206 In acute period following diagnosis, parents often experienced emotions that can be  
207 described as catastrophic, including shock, fearfulness, frustration, hopelessness,  
208 sadness, and feelings that disaster is imminent.

209 Interviewee DM2: "When the doctor told me that my child was diabetic, I felt like [I  
210 was] struck by lightning and the sky was falling. My child's life is basically over."

### 211 **(2) Emotional Distress Based in Negative Emotions**

212 Negative emotions observed in T1DM Caregiver Parents primarily included continual  
213 worry, anxiety, sadness, stigma, annoyance, and guilt. Worry was embodied in anxiety  
214 and sadness, often with connections to the uncertainty of disease progression in their  
215 child. Some parents also experienced symptoms of worry and invasive thoughts about  
216 the potential for their children to be discriminated against in the future because of their  
217 illness, leading some to even report hiding their child's illness in common social  
218 contexts. Further, parents reported feeling guilt linked to social isolation and dietary  
219 restrictions experienced by their child, etiology of illness (often linked to limited  
220 clinical understanding of T1DM), or feeling of being "at fault" for their child's  
221 condition.

222 Interviewee DM2: "It's still like a sword hanging over my head. I don't know when the

1  
2  
3 223 complications will come. I live with fear every day."  
4

5 224 Interviewee DM6: I don't want people around to know that my child has diabetes.  
6

7 225 Diabetes is an undead cancer. Thinking about it in another way, who wants his child to  
8

9 226 marry a diabetic in the future? You may only have to marry someone who also has  
10

11 227 diabetes. My child doesn't want her classmates to know that she is different from  
12

13 228 others."  
14

15 229 Interviewee DM3: "My thoughts are that he is too young and suffers too much. He has  
16

17 230 to get injections and blood tests every day, and his fingers are pierced constantly. As a  
18

19 231 parent, I feel like a failure. I have not taken good care of my child and have been busy  
20

21 232 with work. I feel like I neglect taking care of him."  
22

### 23 233 **(3) Altered Sense of Self-Efficacy**

24 234 T1DM Caregiver Parents also showed self-doubt owing to lack of experience in chronic  
25

26 235 disease care. In the most extreme cases, these feelings manifest as a severe lack of self-  
27

28 236 compassion, wherein parents expressed doubt in their ability to competently care for  
29

30 237 their child.  
31

32 238 Interviewee DM6: "Taking care of [my daughter], it's not that I think I can or can't, but  
33

34 239 that I must be able to. It's like a parent's obligation. If I can't, what else can she do?  
35

36 240 It's not something I can or can't do. It's something I must be able to."  
37

### 38 241 **(4) Perceived Increased Responsibility for Parenting**

39 242 T1DM Caregiver Parents reported perceiving a heavier burden of responsibility to  
40

41 243 manage their child's disease and remain hypervigilant, in particular for young children  
42

43 244 with T1DM not capable of self-managing. Parents perceive that, compared to children  
44

45 245 without T1DM, both parents and children bore additional responsibilities.  
46

47 246 Interviewee DM19: "Now our child is too young to take care of herself. As parents, we  
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49 247 are duty-bound, we have to be good supervisors. We supervise our child's diet, exercise,  
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3 248 blood glucose testing and injections. Although we are not professionals, we will be  
4  
5 249 dedicated to protecting our child's health. "

### 8 250 **Altered Facility Function**

9  
10 251 Changes in family life included two prominent subthemes:

#### 12 252 **(1) Changes in Patterns of Family Life**

14 253 Changes in routine patterns of daily living within the family unit were consistently  
15  
16  
17 254 reported by T1DM Caregiver Parents. These changes included changes in family  
18  
19 255 activities designed to assist children in adapting to their life after T1DM diagnosis. On  
20  
21 256 one hand, parents reported striving to retain normalcy for their children; however, the  
22  
23 257 child's T1DM was also often reported to be disruptive to others, particularly other  
24  
25 258 children, in the family unit. Parents also reported aiming to incorporate blood glucose  
26  
27 259 measurement in routine daily living activities of the family unit, with mixed success.

30 260 Interviewee DM16: "It is inevitable that [when living with a child with T1DM] you  
31  
32 261 can't be the same as other families. We have to consider our child's physical strength  
33  
34 262 and whether [he] can eat regularly. Especially when faced with a table of good food, it  
35  
36 263 is uncomfortable for the child to see others eating.

39 264 Interviewee DM18: "Now we guide our child to think that measuring blood glucose  
40  
41 265 and injecting insulin is a routine in life, just like showers before bed. We don't want  
42  
43 266 our child to feel that injecting insulin before meals is a burden."

#### 47 267 **(2) Changes in Parental Role and Function**

48  
49 268 T1DM Caregiver Parents consistently reported that they perceived differences between  
50  
51 269 their "normal" role and function compared with their prior lifestyle before their child's  
52  
53 270 diagnosis. Specifically, T1DM Caregiver Parents expressed that their child's diagnosis  
54  
55 271 affected their future career planning, life focus, and goals, and often resulting in a  
56  
57 272 greater amount of time spent tending medical needs of their child.  
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3 273 Interviewee DM5: "Now I rarely focus my energy on the company [I work for], just get  
4  
5 274 off work as soon as possible. I used to leave early and return late to make money. Now  
6  
7  
8 275 I quit my job and found a new one that can make a living while taking care of my child.  
9  
10 276 When she is on vacation, so am I."

11  
12 277 In some cases significant housing and job/school changes are made to accommodate  
13  
14 278 the child's T1DM care.

15  
16  
17 279 Interviewee DM14: "My family is in the countryside, but our child comes to a school  
18  
19 280 in the city. Since our child has the disease, diabetes, and cannot live in school, I have  
20  
21 281 to accompany him to study. My child and I rented a house near the school, which is  
22  
23  
24 282 convenient for me to take care of him, and we will return to the countryside during  
25  
26 283 vacation, where his father works.

#### 27 284 **Challenges in Daily Management Theme**

28  
29  
30 285 Challenges in daily management were consistency reported by T1DM Caregiver  
31  
32 286 Parents, including:

##### 33 287 **(1) Technical Difficulties in Blood Glucose Management**

34  
35  
36  
37 288 T1DM Caregiver Parents reported technical difficulties in blood glucose management,  
38  
39 289 including unsatisfactory or irregular blood glucose levels, primarily associated with  
40  
41 290 dietary control, exercise compliance, untimely blood glucose monitoring, and insulin  
42  
43 291 injection dosage adjustment. Parents expressed that lack of self-management, often  
44  
45 292 owing to social and educational obligations, was often a key concern.

46  
47  
48  
49 293 Interviewee DM3: "He is in the second grade of junior high school. There is a lot of  
50  
51 294 tutoring outside school. He has to get up at 5:30 in the morning to study and finish  
52  
53 295 school at 5:30 in the evening. If goes to the tutoring class, he returns at 8:30. There is  
54  
55 296 no time to exercise. At school, his blood glucose control was poor [but] it is impossible  
56  
57 297 to ask him to leave school to take measurements before and after meals."  
58  
59  
60



## 298 (2) Emotional Regulation

299 In addition to the regulation of T1DM Caregiver Parents' own emotions, interviewees  
300 also reported difficulty in assessing and managing their child's emotional and  
301 psychological needs. Interviewee DM14: "[My daughter with T1DM] feels that if her  
302 classmates know she is sick and can't be cured, she will be inferior to others. Often it  
303 was lunch at noon, and she went to the toilet to get an injection, because she is afraid  
304 of being discriminated against by her classmates or something. Our child's self-esteem  
305 is strong, so she ran the toilet for injections; at that time, if another child went to the  
306 toilet, she would be frightened, remove the needle and hurriedly put it away. She would  
307 not press and was still bleeding. As a parent, I feel distressed, but I don't know how to  
308 help the child's feel better

## 309 (3) Managing Parent-Child Conflict

310 Interviewees consistently reported that parent-child conflict stemmed from inability to  
311 communicate effectively and perception of their children's poor compliance with  
312 disease management. As children age and their sense of autonomy increases, parents  
313 reported difficulty in transitioning to stages where their child exerts greater autonomy  
314 over their T1DM care and monitoring. In particular, interviewees reported resistance  
315 from their child, and perceptions that the child felt controlled by the parent's actions.  
316 Interviewee DM20: "I understand that the child is also upset and there is no place to  
317 vent. I restrict her eating and control her blood glucose measurements. How can she not  
318 resist psychologically? I feel that I can't get into her heart, I don't know how to get along  
319 with her."

## 320 (4) Transition from Parental Management to Self-Management as the Child Ages

321 With changes in their child's growth and developmental stage, the roles and function  
322 of children and parents in T1DM management shifts. However, premature transfer of

1  
2  
3 323 diabetes management tasks to children with T1DM is now considered a factor leading  
4  
5 324 to poor blood glucose control. Many T1DM Caregiver Parents expressed uncertainty or  
6  
7  
8 325 frustration on transition timing.

9  
10 326 Interviewee DM15: "In the first year, we helped her with her insulin injections, and  
11  
12 327 then she did it by herself for the next two years. The blood glucose monitoring at night  
13  
14 328 was not done, so the glucose control was not good. Such an old child is really difficult  
15  
16  
17 329 to manage, half-sensible but not sensible."

### 18 19 330 **Excessive Financial Burden Theme**

20  
21 331 T1DM Caregiver Parents consistently reported the excessive financial burden of caring  
22  
23 332 for a child with T1DM, including high cost of treatment. This burden was often cited  
24  
25 333 as a factor for job and educational changes, affecting family member circumstances.  
26  
27 334 Due to the long-term nature of treatment, medications and injection supplies are  
28  
29 335 consumable items with sustained cost impact. Further, caring for a young child with  
30  
31 336 T1DM often requires care around the clock, with some parents reporting that one of  
32  
33 337 parent gave up employment, changed employment, or reduced hours to provide  
34  
35 338 adequate care for their child, often decreasing household income and adding further  
36  
37 339 financial stress to middle- and low-income families.

38  
39 340 Interviewee DM2: "Using an insulin pump is a great economic pressure. It costs nearly  
40  
41 341 20,000 CNY a year. A tube is normally more than 110 CNY. I will buy some during  
42  
43 342 sales and let my friends buy some more from other channels. A tube can be used for  
44  
45 343 three days. It costs nearly 20,000 CNY a year."

### 46 47 344 **Lack of Social Support Systems Theme**

48  
49 345 The lack of support system primarily includes limited social activities and insufficient  
50  
51 346 social support system, as described below:

#### 52 53 347 **(1) Lack of Limited Social Activities**

1  
2  
3 348 At present, the family structure in China is dominated by a typical nuclear family, and  
4  
5 349 children are generally a primary focus of the family unit. Once a child is diagnosed with  
6  
7  
8 350 T1DM, T1DM Caregiver Parents reported feeling disruption in the social activities of  
9  
10 351 the family unit. In particular, mothers in the interview often left their employment,  
11  
12 352 changed careers, or reduced hours to allow for caregiving for their child with T1DM.  
13  
14 353 This transition can result in social isolation and limit normal social activities of the  
15  
16  
17 354 parent.

18  
19 355 Interviewee DM10: "Since my child had a ketosis coma, I have never dared to relax  
20  
21 356 again. I have lost myself. Every day in the year, there are no more visits to relatives or  
22  
23  
24 357 friends."

## 25 26 358 **(2) Insufficient Other Support Systems**

27  
28 359 Insufficient other systems of social support was a common concern of T1DM Caregiver  
29  
30 360 Parents, especially those of children reaching school age and assuming autonomy over  
31  
32  
33 361 their care during school hours.

34  
35 362 Interviewee DM12: "Unlike other countries, our children do not have diabetes nurses  
36  
37 363 in school. When the child is at school, every time the teacher calls, I am terrified, always  
38  
39 364 scared that something bad will happen. If the child's blood glucose is low, does the  
40  
41  
42 365 teacher know how to handle it? Will it be delayed?"

## 43 44 366 **Discussion**

45  
46  
47 367 This study employed qualitative research methods via semi-structured interviews with  
48  
49 368 parental caregivers of children with T1DM. Using Grounded Theory (GT), a method  
50  
51 369 based in social science research, [20-21] the researchers examined and consolidated  
52  
53  
54 370 emergent themes from interview transcripts. GT methods are designed to allow  
55  
56 371 emergence of previously undetected patterns or trends in social communications. In this  
57  
58 372 study, parental caregivers of T1DM children consistently reported Persistent  
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3 373 psychological stress, changes in routine functions of the family unit, challenges in daily  
4  
5 374 disease management for both the child and parental caregiver, financial strain, and  
6  
7 375 disruption of social activities. Thus, this qualitative study and the following sections  
8  
9 376 aim to build on these results to provide actionable insights for both future research and  
10  
11 377 patient support programs.  
12  
13

### 14 378 **Reducing Persistent Psychological Strain in Parental Caregivers of Children with** 15 16 379 **T1DM Experience**

17  
18 380 This study showed that parental caregivers of children with T1DM were particularly  
19  
20 381 susceptible to psychological stress during the early stages after their child's first T1DM  
21  
22 382 diagnosis. These stressors manifested as recollections of negative emotions leading to  
23  
24 383 emotional distress, including shock, sadness, and anxiety. Further, the challenges of  
25  
26 384 repeat insulin injections and finger blood glucose monitoring in child posed not only  
27  
28 385 technical challenges for non-medical professional caregivers, but also emotional  
29  
30 386 distress in parental caregivers. Shortly after a child's diagnosis, many parental  
31  
32 387 caregivers reported feelings of disbelief, resulting in catastrophic emotional  
33  
34 388 disturbances linked to shock, fear, frustration, despair, and sadness. These findings are  
35  
36 389 consistent with other quantitative psychological studies demonstrating posttraumatic  
37  
38 390 stress disorder (PTSD) symptoms in caregivers<sup>20,22-24</sup>; however, the use of qualitative  
39  
40 391 interview methods enables additional insights into the character of reflective  
41  
42 392 perceptions of parental caregivers, and how such stress can be relieved. Our study  
43  
44 393 suggests that the emotional effects of "invisibility" of the condition prior to diagnosis  
45  
46 394 can trigger guilt and anxiety that exacerbate psychological stressors. Further, young age  
47  
48 395 of the child and uncertainty of social impact can also exacerbate the psychological  
49  
50 396 effects on the caregiver, leading to heightened anxiety and PTSD manifestations. In  
51  
52 397 some cases, these stressors can lead to catastrophic emotional experiences occurred in  
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3 398 the early stage of diagnosis and during a child's hospitalization, which is consistent  
4  
5 399 with other research<sup>25</sup>.

6  
7 400 In particular, following the hospital discharge of a child with T1DM, parental  
8  
9 401 caregivers in this study exhibited heightened emotions, characterized by poorly  
10  
11 402 controlled worry, anxiety, sadness, stigma, annoyance, and guilt. During the course of  
12  
13 403 our interviews, it emerged that worry, anxiety, and sorrow were closely linked to  
14  
15 404 uncertainty of disease progression. This observation is consistent with prior studies that  
16  
17 405 have shown parental caregivers of children with T1DM experience a heightened level  
18  
19 406 of disease uncertainty compared to caregivers of other chronic disease states, which can  
20  
21 407 exert adverse effects on the health and psychological condition of the parental  
22  
23 408 caregivers and the children they care for<sup>26</sup>. Thus, medical staff should pay particular  
24  
25 409 attention to these potential effects in parental caregivers.

26  
27 410 Parental caregivers, in part due to their emotional bond with their child, are also affected  
28  
29 411 by emotionally by perceived stigma. Stigma refers to a kind of inner shame caused by  
30  
31 412 illness that is perceived a deficiency, which negatively affects patient psychology and  
32  
33 413 can contribute noncompliance or delay of critical treatment and monitoring in T1DM<sup>27</sup>.  
34  
35 414 During the interviews conducted in this study, some parents of children with T1DM  
36  
37 415 expressed that diabetes would affect their child's future employment, marriage, and  
38  
39 416 social standing, in some cases going so far as to hide their child's to avoid perceived  
40  
41 417 discrimination. Stigma affects caregivers by playing on their guilt, which may be  
42  
43 418 exacerbated by "causing" the child pain through blood tests and limiting activities or  
44  
45 419 diet. Some parents also have limited scientific understanding of the illness, and perceive  
46  
47 420 the disease to be a result of negligent in care that can further exacerbate feeling of guilt,  
48  
49 421 anxiety, and depression in caregivers. Parent's persistent emotional distress affects their  
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51 422 own physical and mental health, thereby affecting management of blood glucose  
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3 423 control in their children<sup>28</sup>. Thus, the emotional state of the parental caregiver is of  
4  
5 424 concern to medical staff treating children with T1DM.  
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7

8 425 As prior research has shown, the self-efficacy of parental caregivers in diabetes  
9  
10 426 management is related to the effectiveness of blood glucose control<sup>29</sup>. In the interviews  
11  
12 427 conducted in this study, parental caregivers emphasized expectations placed on the  
13  
14 428 mother's role, and their increased sense of self-efficacy. Parents that perceived  
15  
16 429 themselves as competent in the role of caregiver consistency experienced less emotional  
17  
18 430 distress. Through analyzing interviews, this study found that the psychological burden  
19  
20 431 of parents primarily derives from the following courses: (1) Pressure of blood glucose  
21  
22 432 management in children, especially in diet management; (2) Children's physical and  
23  
24 433 mental pain caused by insulin injections, blood glucose monitoring, and diet restrictions;  
25  
26 434 (3) Mood changes in children due to illness; and (4) The impact of the disease on the  
27  
28 435 future of the children. These insights can be used to design integrated patient  
29  
30 436 management programs that consider both parental caregiver emotional health and the  
31  
32 437 medical condition of the T1DM child.  
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### 37 438 **Supporting the Transition of Parents into an Evolving Caregiver Role**

38  
39 439 Becoming a caregiver of child with T1DM is disruptive not only to the parent(s), but  
40  
41 440 also to the family unit. Further, the emotional burden on parental caregivers is increased  
42  
43 441 by an evolving need for autonomy over T1DM care as young children age. For younger  
44  
45 442 children with T1DM, parental caregivers will need to dedicate substantial time and  
46  
47 443 financial resources to their child's daily care, such as regular blood glucose  
48  
49 444 measurement, injecting insulin, monitoring their diet and physical activities, and  
50  
51 445 handling emergent issues. Common challenges in daily management include difficulty  
52  
53 446 in blood glucose management, emotional management, parent-child conflict, and the  
54  
55 447 transition from parental management to self-management. While technology has  
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3 448 improved T1DM care through the use of insulin pumps and continuous blood glucose  
4  
5 449 monitoring, often young children may not have access to these technologies or  
6  
7 450 compliance may not be possible<sup>30</sup>. These changes in activities of daily living in the  
8  
9 451 family unit also impact relationships between parents and children, can lead to conflict.  
10  
11 452 Thus, additional support is needed in the community and clinical setting to support  
12  
13 453 parents transitioning through the various stages of T1DM caregiver roles.  
14  
15 454 Parental caregivers of children with T1DM also face challenges in transitioning their  
16  
17 455 role to give their child gained increased autonomy with age. In this study, it was  
18  
19 456 apparent from interviews that, even at a young age, issues of the child's autonomy could  
20  
21 457 affect the parent-child relationship and lead to family conflict. Studies have shown that  
22  
23 458 in families experience conflicts in chronic disease care settings. In particular, children  
24  
25 459 with T1DM and high levels of family conflict have been shown to have poorer blood  
26  
27 460 glucose control and lower overall quality of life<sup>31,32</sup>. As young children grow into  
28  
29 461 adolescents, these conflicts may become more common or escalate. Khandan (2018)<sup>33</sup>  
30  
31 462 found that when children with T1DM reached the age of 8 to 11, their parents begin to  
32  
33 463 transfer diabetes management responsibility to them, gradually transitioning from  
34  
35 464 "parental responsibility" to "cooperative support." While parents have a high degree of  
36  
37 465 control over their young child's medical care, they may require outside support for  
38  
39 466 clinicians or the community in transitioning these responsibilities as their child enters  
40  
41 467 adolescents. Appropriate mental health and community support may thus improve  
42  
43 468 outcomes among these children and their caregivers and help to achieve an effective  
44  
45 469 transition to self-management as these children enter adolescence.  
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#### 470 **Improving Financial and Social Support Systems for Parental Caregivers of** 471 **Children with T1DM in China**

472 In this study, parental caregivers of children with T1DM consistency reported a strain

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2  
3 473 on household finances related to their child's care and disposable supplies, and a lack  
4  
5 474 of social support. Similar to the results of other studies<sup>34</sup>, medications and disposable  
6  
7 475 devices used for long-term treatment place a substantial and ongoing burden on these  
8  
9 476 families, often affecting housing, employment, and economic opportunities for middle-  
10  
11 477 and low-income families. Financial burden can affect the physical and mental health of  
12  
13 478 parental caregivers, also limit or delay selection of treatment options that can influence  
14  
15 479 the T1DM child's long-term prognosis.

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18  
19 480 Further, the lack of social support and relative social isolation of caregivers, particularly  
20  
21 481 those that reduces hours or left jobs to act as primary caregivers (most common among  
22  
23 482 mothers), was consistently reported in this study. The lack of support systems was  
24  
25 483 apparent from limited family social activities, which often negatively impacted the  
26  
27 484 parental caregiver's emotional state. Further, compared to other developed regions,  
28  
29 485 China has currently has a lack of diabetes nurses in kindergartens and primary and  
30  
31 486 secondary schools. Thus, preschool and school-age children have to assume the  
32  
33 487 responsibility of diabetes self-management during school hours. Furthermore, because  
34  
35 488 of self-esteem issues or poor self-control, many parents we studied reported that their  
36  
37 489 blood sugar control was not ideal during school. Therefore, we propose that we should,  
38  
39 490 as a healthcare system, selectively learn from the successful experience of other  
40  
41 491 countries and gradually implement training for school personnel and other personnel  
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43 492 who come into contact with diabetic children to improve the social support system for  
44  
45 493 children with diabetes.

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51 494 Notably, this research is limited by the interpretation of the reviewers and coders. In  
52  
53 495 particular, all interviewees and researchers were from a single hospital, which limits  
54  
55 496 the generalizability of the findings of this study to a broader population. However, these  
56  
57 497 insights provide greater depth than mere quantitative characterizations, and provide  
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3 498 essential insights to improving both psychological and physical outcomes of children  
4  
5 499 with T1DM and their parental caregivers.  
6  
7

## 8 500 **Conclusions**

9  
10 501 Through a series of interviews that examined the perceptions of parental caregivers of  
11  
12 502 children with T1DM, this qualitative study employs grounded theory methods to  
13  
14 503 examine the emergent themes in these conversations, often anecdotally experiences by  
15  
16 504 health care professionals. This research gives voice to the common challenges faces by  
17  
18 505 parental caregivers as their young children are first diagnosed with T1DM and slowly  
19  
20 506 gain autonomy for their own chronic disease management with age. This research  
21  
22 507 demonstrated common themes of persistent psychological stress, difficulty managing  
23  
24 508 changes in family function, challenges in daily disease management, challenges of  
25  
26 509 excessive financial burden, and the impact of a lack of social support for parental  
27  
28 510 caregivers. By characterizing these common perceptions and experiences, we can better  
29  
30 511 prepare health care providers to support both the T1DM child and parental as they adapt  
31  
32 512 to medical management of T1DM at different life stages, thereby improving home self-  
33  
34 513 management capabilities.  
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## 40 514 **List of abbreviations**

41  
42 515 T1DM: Type 1 Diabetes Mellitus  
43  
44 516 QoL: Quality of life  
45  
46 517 GT: Grounded Theory  
47  
48 518 PTSD: posttraumatic stress disorder  
49  
50 519 IRB: Institutional Review Board  
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4

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8

9  
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11  
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13  
14 526 Huijuan Tong. The manuscript was written by Huijuan Tong and Ling Fan.  
15

16  
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18  
19 528 with the Declaration of Helsinki and was approved by the Institutional Review Board  
20  
21 529 (IRB) of Shengjing Hospital, China Medical University, Shenyang, China (Approval  
22  
23 530 no. 2018PS362K). All participants provided written informed consent prior to  
24  
25 531 participating in interviews.  
26  
27

28 532 **Consent for publication:** Not applicable  
29

30 533 **Availability of data and materials:** The data set supporting the results of this article  
31  
32 534 are included within the article. The datasets used and/or analysed during the current  
33  
34 535 study are available from the corresponding author on reasonable request.  
35  
36

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43  
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46

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645 **Table 1 Semi-Structured Interview Outline for Parents of Children Aged  $\leq 14$  with**  
 646 **Type 1 Diabetes Mellitus (T1DM Caregiving Parents)**

| Question # | Description  |
|------------|--|
| 1          | Could you please talk about the situation when your child was first diagnosed with type 1 diabetes and your reaction at that time?               |
| 2          | Could you please describe a day of caring for a child with type 1 diabetes?  |
| 3          | Since your child was diagnosed with diabetes, what has been your biggest concern, or what is the most difficult issue you have had to deal with? |
| 4          | How do you help your child manage his/her diet?  |
| 5          | How do you help your child manage his/her medication?  |
| 6          | How do you help your child manage his/her activities or exercise?  |
| 7          | How do you help your child manage his/her emotions?  |
| 8          | How do you manage your own life while taking care of your child?   |
| 9          | As a caregiver, what are your needs in caring for the child?   |
| 10         | Do you think you are qualified for the role of caring for a child with type 1 diabetes?  |

647 Note: This outline has been translated from the original Mandarin Chinese version. All  
 648 interviews were conducted in the local language of the investigator (Mandarin  
 649 Chinese).



651 **Table 2 Characteristics of Parental Caregivers of T1DM Children (T1DM**  
 652 **Caregiver Parents) Interviewed**

| Characteristic                                  | Interviewee<br>(n = 20) |
|---|-------------------------|
| Children  |                         |
| Age (years), mean±SD                            | 10.6±2.45               |
| Onset age of T1DM, mean±SD                      | 7.2±2.4                 |
| Insulin regimen, n (%)                          |                         |
| Insulin pump use                                | 8 (40%)                 |
| Daily injections                                | 12 (60%)                |
| Gender, n(%)                                    |                         |
| Male  | 7 (35%)                 |
| Female  | 13 (65%)                |
| Parents   |                         |
| Age(year), mean±SD                              | 39.45±6.21              |
| Gender, n (%)                                   |                         |
| Male (self-identify as Father)                  | 8(40%)                  |
| Female (self-identify as Mother)                | 12(60%)                 |
| Current employment status, n (%)                |                         |
| Full-time                                       | 8 (40%)                 |
| Part-time                                       | 6 (30%)                 |
| Not working                                     | 6 (30%)                 |
| Highest education level, n (%)                  |                         |
| Junior high (middle) school or some high school | 6 (30%)                 |
| High school diploma                             | 6 (30%)                 |

|    |   |         |
|----|---|---------|
| 1  |   |         |
| 2  |   |         |
| 3  | Technical school (2-year degree or equivalent)  | 3 (15%) |
| 4  |   |         |
| 5  | Bachelor's degree (4-year degree or equivalent) | 5 (25%) |
| 6  |   |         |
| 7  | Monthly Income (CNY), n (%)                     |         |
| 8  |   |         |
| 9  |   |         |
| 10 | < 3077  | 5 (25%) |
| 11 |   |         |
| 12 | 3077 to -11428                                  | 9 (45%) |
| 13 |   |         |
| 14 | >11428  | 6 (30%) |
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654 **Table 3 Themes and Sub-themes Emerging from Interviews of Parental**  
 655 **Caregivers of T1DM Children (T1DM Caregiver Parents)**

| Themes                          |  | Subthemes  |
|---------------------------------|--|--|
| Persistent psychological stress |  | (1) catastrophic emotional experience  |
|                                 |  | (2) emotional distress based in negative emotions                            |
|                                 |  | (3) altered sense of self-efficacy   |
|                                 |  | (4) perceived increased responsibility for parenting                         |
| Family function changes         |  | (1) changes in patterns of family life                                       |
|                                 |  | (2) changes in parental roles and functions                                  |
| Challenges in daily management  |  | (1) technical difficulties managing blood glucose                            |
|                                 |  | (2) difficulties in regulating emotion                                       |
|                                 |  | (3) managing parent-child conflict   |
|                                 |  | (4) transition from parental management to self-management as the child ages |
| Excessive financial burden      |  | (1) burden of disease treatment  |
|                                 |  | (2) changes in economic sources  |
| Lack of social support system   |  | (1) limited social activities  |
|                                 |  | (2) insufficient other support systems                                       |

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# BMJ Open

## Characterizing Common Challenges Faced by Parental Caregivers of Children with Type 1 Diabetes Mellitus in Mainland China: A qualitative study

|                                 |  |
|---------------------------------|--|
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| <b>Primary Subject Heading</b>: | Diabetes and endocrinology   |
| Secondary Subject Heading:      | Diabetes and endocrinology   |
| Keywords:                       | DIABETES & ENDOCRINOLOGY, General diabetes < DIABETES & ENDOCRINOLOGY, General endocrinology < DIABETES & ENDOCRINOLOGY  |
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3 **Characterizing Common Challenges Faced by Parental Caregivers of Children**  
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5 **with Type 1 Diabetes Mellitus in Mainland China: A qualitative study**  
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## Abstract

**Objectives:** Mental state of parental caregiver affects outcomes in children with Type 1 Diabetes Mellitus (T1DM). This study aimed to qualitatively examine perception of common challenges among parental caregivers of children with T1DM.

**Setting:** 45-60 minutes long semi-structured interviews were conducted with T1DM Parental Caregivers. Interview recordings were transcribed and coded in NVivo 11.0 to observe emergent themes.

**Participants:** Eligible T1DM Caregiving Parents (parent(s) and/or legal guardian(s)) were identified from caregivers attending visits with children hospitalized or assessed in the Pediatric Neuroendocrinology Department of Shengjing Hospital, China Medical University in Shenyang from January 2018 to June 2019.

**Primary and secondary outcome measures:** Not applicable.

**Results:** A total of 20 T1DM Caregiving Parents were interviewed, aged 30 to 53 years, including 7 fathers and 13 mothers, with their children mean age of  $10.6 \pm 2.45$  years. Content analysis revealed 5 common themes with 13 subthemes, including persistent psychological stress (catastrophic emotions, emotional distress, and altered self-efficacy), family function change (altered family life patterns and changes in parental role/function), challenges in daily management (technical challenges, emotional regulation, parent-child conflict, and transition of care autonomy from parent to child), financial burden (cost burden of treatment and altered family economics), and lack of social support (social activity limitations and insufficient support systems).

**Conclusions:** Period of emotional disturbance during initial diagnosis, psychological stresses of long-term caregiving, and conflict emerging from transition from parental to child responsibility all can cause psychological effects detrimental to parental caregivers and T1DM children. This work provides compelling evidence for the role of

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3 assessment and intervention in parental caregiver psychological and emotional  
4 wellbeing in diabetes care, as well as the need for improved social and school support  
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6 for children with T1DM in China.  
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12 **Keywords:** Type 1 Diabetes Mellitus, Grounded Theory, Qualitative Methods,  
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14 Caregiving, Diabetes Care, Psychological Perceptions  
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### 17 18 19 **Strengths and limitations of this study**

- 20  
21  
22 1. This is the first study, which describes the conditions and consequences of young  
23 children with T1DM relying on parental caregivers for disease management in China.  
24  
25 2. This study demonstrates that period of emotional disturbance during initial  
26 diagnosis, psychological stresses of long-term caregiving, and conflict emerging from  
27 transition for parental to child responsibility can cause psychological effects  
28 detrimental to parental caregivers and T1DM children.  
29  
30 3. This study provides compelling evidence for the role of assessment and  
31 intervention in parental caregiver psychological and emotional wellbeing in diabetes  
32 care.  
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34 4. This study is limited by the interpretation of the reviewers and coders.  
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36 5. This is a single-center study, with limited generalizability of the findings, and a  
37 further multicenter study was needed.  
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### 49 **Introduction**

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51 Type 1 Diabetes Mellitus (T1DM) is a common enough chronic disease in children,  
52 and both the parental caregiver as well as the child diagnosed with T1DM must partake  
53 on management of disease associated tasks, with underlying financial, emotional, and  
54 social impact on the family unit[1]. With the incidence of T1DM increasing by 2% to  
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3 5% each year worldwide[2], an increasing number of families with young children are  
4 influenced by its burden. Although the incidence of T1DM in China is lower than that  
5 in Europe or the United States, being currently 5.6 per 100,000 live births[3], China  
6 ranks fourth among countries for T1DM occurrence — and the number of cases is  
7 increasing each year[4]. However, rural communities in China generally have fewer  
8 resources and growing number of T1DM cases outside of urban centers would  
9 eventually increase the strain on Chinese parental caregivers. Thus, examining the  
10 situation of middle- and low-income parents of children with T1DM in China is  
11 essential to improving resources for T1DM care and long-term outcomes.  
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23 Management of T1DM in children involves changes in daily living activities that affect  
24 not only the child receiving care but also the caregiver, including responsibility to  
25 ensure continuous glucose monitoring (4 or more times per day) and insulin injection  
26 using an insulin pump or injecting insulin multiple times a day, as well as tracking and  
27 calculating daily carbohydrate intake and physical activity levels important to  
28 prevention of hypoglycemic and hyperglycemic episodes[5, 6]. Majority of children  
29 with T1DM under age of 13 are unable to self-manage their T1DM care, and instead  
30 rely heavily on their parental caregiver for disease management[7]. Treatment for  
31 children with T1DM is aimed at ensuring stable blood glucose levels, minimizing  
32 occurrence of potentially severe hypoglycemic events, and preventing long-term  
33 complications of diabetes as the child grows[8]. These responsibilities presumably  
34 place immense psychological and financial stress on parental caregivers.  
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50 Owing to the relatively lower incidence of T1DM outside of urban centers in China,  
51 the emotional toll, financial burden, and social isolation experienced by parental  
52 caregivers of young children with T1DM can be immense. Despite improvements in  
53 T1DM medications and treatment technologies, many children still experience adverse  
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3 health effects due to invasive procedures or ineffective blood glucose control[9]. Recent  
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5 research suggests that, more than 58.6% of children with T1DM in China do not achieve  
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7 sustained hemoglobin control (glycosylated hemoglobin lower than 7.5%)[10]. This  
8  
9 can lead to complications, that have adverse impact on the child's growth and long-  
10  
11 term health, and place significant burden on caregivers and the family unit. Thus, there  
12  
13 is a need to study T1DM care, and its impact on parental caregivers, through a social  
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15 lens.  
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18  
19 Rankin et al. (2018)[1] used qualitative methods to examine the strategies and  
20  
21 motivations of children with T1DM and their caregivers, providing insights into how  
22  
23 diabetes management can be improved. Other researchers have also demonstrated that  
24  
25 successful disease management of children with T1DM not only requires the children  
26  
27 to manage their individual health, but also requires their cooperation with caregivers  
28  
29 who share the responsibility for the child's medical management[11]. These burdens  
30  
31 can, however, result in caregiving parents of children with T1DM feeling isolated and  
32  
33 helpless when faced with the challenges of chronic disease management.  
34  
35 Psychologically, caregivers may manifest a sense of self-doubt, guilt, or anxiety, and  
36  
37 many of them experience traumatic initial confusion as they try to integrate these new  
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39 responsibilities into their family's routine when their child is first diagnosed[12]. These  
40  
41 feelings may be transient or persist, and may be exacerbated if a child experiences  
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43 hypoglycemic events or other emergency situations that contributes to caregiver trauma  
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45 and anxiety[13-15]. Understanding the experiences of parental caregivers of children  
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47 with T1DM could greatly improve clinical and social interventions to help parents adapt  
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49 to the role of caregiver, and achieve optimal health outcomes for their children.  
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51 However, current research on children with T1DM in China is primarily limited to  
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53 quantitative studies on the quality of life (QoL)[15], psychological state[16] and coping  
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3 style of the children or their parents[17].  
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5 Qualitative research methodologies can provide actionable insights into the  
6 psychological state, behaviors, and motivations of patients and caregivers managing  
7 T1DM[1]. This study employs qualitative methods to examine the perceptions of  
8 parental caregivers of young children (aged 14 or younger) with T1DM in China,  
9 providing insights into the key challenges as caregivers transition from complete  
10 management of young children with T1DM to an older child with increasing autonomy  
11 over his or her medical care. Thus, this research is designed to provide actionable  
12 insights for improving social support and management of these patients, in a holistic  
13 context that considers the parental caregiver and family unit.  
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## 28 **Methods**

### 29 **Patient and Public Involvement**

30 Patients or the public were not involved in the design, or conduct, or reporting, or  
31 dissemination plans of our research.  
32

### 33 **Study Population and Design**

34 Qualitative research methods were employed to examine social, emotional, and  
35 experiential perceptions of parent(s) and/or legal guardian(s) with children diagnosed  
36 with T1DM, referred to as T1DM Caregiving Parent for purposes of this article.  
37 Synchronous, in-person, semi-structured interviews were conducted to collect  
38 qualitative data, and emergent heuristic content analysis was subsequently performed  
39 on transcripts. Eligible T1DM Caregiving Parents were identified from caregivers  
40 attending visits with children hospitalized or assessed in the Pediatric  
41 Neuroendocrinology Department of Shengjing Hospital, China Medical University in  
42 Shenyang from January 2018 to June 2019.  
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3 To be eligible for participation in study interview, T1DM Caregiving Parents were  
4 required to (1) be the parent and/or legal guardian of a child 14 years of age or younger  
5 with diagnosed T1DM, and (2) be a primary caregiver during at least 6 months of  
6 continuous care for child being treated for T1DM during this period[18] T1DM  
7 Caregiving Parents were considered ineligible to participate in interviews if (1) the  
8 child with T1DM also experienced other significant comorbidities or chronic diseases;  
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12  
13 Caregiving Parents were considered ineligible to participate in interviews if (1) the  
14 child with T1DM also experienced other significant comorbidities or chronic diseases;  
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17 (2) the child with T1DM was considered to require immediate medical care or treatment  
18 and the study could pose an undue burden on the patient or caregiver; (3) T1DM  
19 Caregiving Parent was unable to communicate fluently in the local language of the  
20 investigator (Mandarin Chinese).  
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26 This study was conducted in accordance with the Declaration of Helsinki and was  
27 approved by the Institutional Review Board (IRB) of Shengjing Hospital, China  
28 Medical University, Shenyang, China (Approval no. 2018PS362K). All participants  
29 provided written informed consent prior to participating in interviews.  
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### 35 **Sampling Methods and Process**

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37 Purposive nonprobability sampling was used, in which eligible T1DM Caregiving  
38 Parents were approached for participation as they visited clinic. To ensure a  
39 representative sample, the heterogeneity of sample selection was expanded for T1DM  
40 Caregiving Parent age, marital status, education level, and T1DM child age and disease  
41 course. The study was discontinued when qualitative data reached saturation, which  
42 was expected to occur between 15 and 20 interviews, as previously described[19, 20]  
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### 56 **Data Collection**

58 An IRB-approved semi-structured interview outline was used to ensure consistency

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3 while performing interviews. The interview structure was based on the theory of  
4 individual and family self-management[21], and formulated through expert evaluation  
5 of the research purpose, population, and existent body of literature. The outline used in  
6 interviews is shown in **Table 1**. The planned duration of the interview was 45 to 60  
7 minutes.  
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14 Upon arrival at the clinical site, the head nurse of the clinical unit familiar with the  
15 T1DM Caregiving Parent met the interviewee, led them to the interview site, and made  
16 introductions. Prior to the start of the interview, the interviewer explained the purpose,  
17 significance, methods, rights of the interviewee, and privacy protection measures.  
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19 Written informed consent was then obtained before starting each interview.  
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26 The interview location was selected as audio visual classroom located in the Pediatric  
27 Neuroendocrinology Ward. This location was selected for the quiet environment, free  
28 of distractions. Interviews were conducted by the authors, who were provided with  
29 training on semi-structured interviews and use of neutral, objective, and non-leading  
30 language during the interview to maximize data integrity.  
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### 33 34 35 36 37 **Data Transcription and Coding**

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40 Each interview was recorded using audio recording devices, and digitally transcribed  
41 asynchronously (with 48 hours after each interview) by the researchers. Transcripts  
42 were recorded in MS Word (Microsoft, USA), and verified by a second researcher. To  
43 ensure data integrity, interviewees were provided with a copy of their interview  
44 transcript and allowed to suggest corrections, which, if appropriate, were assessed and  
45 integrated by the researchers upon review of the original recording.  
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53 Heuristic coding was performed using emergent grounded theory methods[20]  
54 manually using transcripts imported into NVivo 11.0 (QSR International, USA) using  
55 manual code to summarize text data, and identify and refine themes. Coding was  
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3 verified by a second researcher, the numbers were used to identify the interviewees in  
4 place of their real names, DM1-DM20. Emergent themes and subthemes were identified  
5  
6 using a grounded theory approach.  
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### 10 **Data Analysis and Reporting**

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12 Textual coding results in NVivo 11.0 were reported as counts and percentages (data not  
13 shown) and themes/sub-themes were presented descriptively using qualitative analysis  
14 methods. All analyses were performed in the local language of the interview conduct  
15 (Mandarin Chinese), and the data were analyzed and collected simultaneously. The  
16 theme of the interviews was extracted using content analysis methodology by way of  
17 three-grade coding. Final results were translated to English, and all translations were  
18 performed by the researchers to ensure integrity of translations.  
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## 31 **Results**

### 32 **Participant Characteristics**

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34 Saturation was reached when 20 T1DM Caregiving Parents (N = 20) completed  
35 interviews. Interviewed T1DM Caregiving Parents included 7 fathers and 13 mothers  
36 (gender roles were self-identified by the interviewee), aged 30 to 53 years, with their  
37 children mean age of 10.6±2.45 years. Of these patients, 8 were caregivers of children  
38 with T1DM that were treated with insulin pumps, and 12 were caregivers of children  
39 with T1DM that were treated with subcutaneous injections. Socio-demographic  
40 information for T1DM Caregiving Parents completing interviews and demographic and  
41 clinical condition of their children are summarized in **Table 2**.  
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54 By analyzing the transcripts of interviews, five emergent themes were observed  
55 consistently throughout the interview data: (1) persistent psychological stress; (2)  
56 family function changes; (3) challenges in daily management; (4) excessive economic  
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3 burden; (5) lack of support system. All 13 subthemes within these 5 themes, are  
4  
5 summarized in **Table 3**. The themes/sub-themes are further characterized below.  
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### 8 **Theme of Persistent Psychological Stress**

9

10 Persistent psychological stress was identified as prominent theme across interviews,  
11  
12 with four key sub-themes emerging from coding:  
13  
14

#### 15 **(1) Catastrophic Emotional Experience**

16

17 In acute period following diagnosis, parents often experienced emotions that can be  
18  
19 described as catastrophic, including shock, fearfulness, frustration, hopelessness,  
20  
21 sadness, and feelings that disaster is imminent.  
22  
23

24 Interviewee DM2: "When the doctor told me that my child was diabetic, I felt like [I  
25  
26 was] struck by lightning and the sky was falling. My child's life is basically over."  
27  
28

#### 29 **(2) Emotional Distress Based in Negative Emotions**

30

31 Negative emotions observed in T1DM Caregiver Parents primarily included continual  
32  
33 worry, anxiety, sadness, stigma, annoyance, and guilt. Worry was embodied in anxiety  
34  
35 and sadness, often with connections to the uncertainty of disease progression in their  
36  
37 child. Some parents also experienced symptoms of worry and invasive thoughts about  
38  
39 the potential for their children to be discriminated in the future because of their illness,  
40  
41 leading some to even report hiding their child's illness in common social contexts.  
42  
43 Further, parents reported feeling guilt linked to social isolation and dietary restrictions  
44  
45 experienced by their child, etiology of illness (often linked to limited clinical  
46  
47 understanding of T1DM), or feeling of being "at fault" for their child's condition.  
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50  
51 Interviewee DM2: "It's still like a sword hanging over my head. I don't know when the  
52  
53 complications will come. I live with fear every day."  
54  
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56 Interviewee DM6: I don't want people around to know that my child has diabetes.  
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58 Diabetes is an undead cancer. Thinking about it in another way, who wants his child to  
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3 marry a diabetic in the future? You may only have to marry someone who also has  
4 diabetes. My child doesn't want her classmates to know that she is different from  
5 others."  
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10 Interviewee DM3: "My thoughts are that he is too young and suffers too much. He has  
11 to get injections and blood tests every day, and his fingers are pierced constantly. As a  
12 parent, I feel like a failure. I have not taken good care of my child and have been busy  
13 with work. I feel like I neglect taking care of him."  
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### 19 **(3) Altered Sense of Self-Efficacy**

20 T1DM Caregiver Parents also showed self-doubt owing to lack of experience in chronic  
21 disease care. In the most extreme cases, these feelings manifest as a severe lack of self-  
22 compassion, wherein parents expressed doubt in their ability to competently care for  
23 their child.  
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30 Interviewee DM6: "Taking care of [my daughter], it's not that I think I can or can't, but  
31 that I must be able to do. It's like a parent's obligation. If I can't, what else can she do?  
32 It's not something I can or can't do. It's something I must be able to do."  
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### 38 **(4) Perceived Increased Responsibility for Parenting**

39 T1DM Caregiver Parents reported perceiving a heavier burden of responsibility to  
40 manage their child's disease and remain hypervigilant, in particular for young children  
41 with T1DM not capable of self-managing. Parents perceive that, compared to children  
42 without T1DM, both parents and children bore additional responsibilities.  
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49 Interviewee DM19: "Now our child is too young to take care of herself. As parents, we  
50 are duty-bound, we have to be good supervisors. We supervise our child's diet, exercise,  
51 blood glucose testing and injections. Although we are not professionals, we will be  
52 dedicated to protecting our child's health. "  
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### 58 **Altered Facility Function**



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3 Changes in family life included two prominent subthemes:  
4

5 **(1) Changes in Patterns of Family Life**  
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7

8 Changes in routine patterns of daily living within the family unit were consistently  
9 reported by T1DM Caregiver Parents. These changes included changes in family  
10 activities designed to assist children in adapting to their life after T1DM diagnosis. On  
11 one hand, parents reported striving to retain normalcy for their children; however, the  
12 child's T1DM was also often reported to be disruptive to others, particularly other  
13 children, in the family unit. Parents also reported aiming to incorporate blood glucose  
14 measurement in routine daily living activities of the family unit, with mixed success.  
15

16 Interviewee DM16: "It is inevitable that [when living with a child with T1DM] you  
17 can't be the same as other families. We have to consider our child's physical strength  
18 and whether [he] can eat regularly. Especially when faced with a table full of good food,  
19 it is uncomfortable for the child to see others eating."  
20  
21

22 Interviewee DM18: "Now we guide our child to think that measuring blood glucose  
23 and injecting insulin is a routine in life, just like showers before bed. We don't want  
24 our child to feel that injecting insulin before meals is a burden."  
25  
26

27 **(2) Changes in Parental Role and Function**  
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30 T1DM Caregiver Parents consistently reported that they perceived differences between  
31 their "normal" role and function compared with their prior lifestyle before their child's  
32 diagnosis. Specifically, T1DM Caregiver Parents expressed that their child's diagnosis  
33 affected their future career planning, life focus, and goals, and often resulting in a  
34 greater amount of time spent tending medical needs of their child.  
35  
36

37 Interviewee DM5: "Now I rarely focus my energy on the company [I work for], just get  
38 off work as soon as possible. I used to leave early and return late to make money. Now  
39 I quit my job and found a new one that can make a living while taking care of my child.  
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3 When she is on vacation, so am I.”  
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6 In some cases significant housing and job/school changes are made to accommodate  
7  
8 the child’s T1DM care.  
9

10 Interviewee DM14: "My family is in the countryside, but our child comes to a school  
11  
12 in the city. Since our child has the disease, diabetes, and cannot live in school, I have  
13  
14 to accompany him to study. My child and I rented a house near the school, which is  
15  
16 convenient for me to take care of him, and we will return to the countryside during  
17  
18 vacation, where his father works.  
19  
20

### 21 **Challenges in Daily Management Theme**

22  
23 Challenges in daily management were consistency reported by T1DM Caregiver  
24  
25 Parents, including:  
26  
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#### 28 **(1) Technical Difficulties in Blood Glucose Management**

29  
30 T1DM Caregiver Parents reported technical difficulties in blood glucose management,  
31  
32 including unsatisfactory or irregular blood glucose levels, primarily associated with  
33  
34 dietary control, exercise compliance, untimely blood glucose monitoring, and insulin  
35  
36 injection dosage adjustment. Parents expressed that lack of self-management, often  
37  
38 owing to social and educational obligations, was often a key concern.  
39  
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41  
42 Interviewee DM3: "He is in the second grade of junior high school. There is a lot of  
43  
44 tutoring outside school. He has to get up at 5:30 in the morning to study and finish  
45  
46 school at 5:30 in the evening. If goes to the tutoring class, he returns at 8:30. There is  
47  
48 no time to exercise. At school, his blood glucose control was poor [but] it is impossible  
49  
50 to ask him to leave school to take measurements before and after meals."  
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#### 53 **(2) Emotional Regulation and Managing Parent-Child Conflict**

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55 In addition to the regulation of T1DM Caregiver Parents’ own emotions, interviewees  
56  
57 also reported difficulty in assessing and managing their child’s emotional and  
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3 psychological needs.  
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5 Interviewee DM14: "[My daughter with T1DM] feels that if her classmates know she  
6 is sick and can't be cured, she will be inferior to others. Often it was lunch at noon, and  
7 she went to the toilet to get an injection, because she is afraid of being discriminated  
8 against by her classmates or something. Our child's self-esteem is strong, so she ran to  
9 the toilet for injections; at that time, if another child went to the toilet, she would be  
10 frightened, remove the needle and hurriedly put it away. She would not press and was  
11 still bleeding. As a parent, I feel distressed, but I don't know how to help the child to  
12 feel better." Interviewees consistently reported that parent-child conflict stemmed from  
13 inability to communicate effectively and perception of their children's poor compliance  
14 with disease management. As children age and their sense of autonomy increases,  
15 parents reported difficulty in transitioning to stages where their child exerts greater  
16 autonomy over their T1DM care and monitoring. In particular, interviewees reported  
17 resistance from their child, and perceptions that the child felt controlled by the parent's  
18 actions.  
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37 Interviewee DM20: "I understand that the child is also upset and there is no place to  
38 vent. I restrict her diet and control her blood glucose measurements. How can she not  
39 resist psychologically? I feel that I can't get into her heart, I don't know how to get along  
40 with her."  
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### 47 **(3) Transition from Parental Management to Self-Management as the Child Ages**

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49 With changes in their child's growth and developmental stage, the roles and function  
50 of children and parents in T1DM management shifts. However, premature transfer of  
51 diabetes management tasks to children with T1DM is now considered a factor leading  
52 to poor blood glucose control. Many T1DM Caregiver Parents expressed uncertainty or  
53 frustration on transition timing.  
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3 Interviewee DM15: "In the first year, we helped her with her insulin injections, and  
4 then she did it by herself for the next two years. The blood glucose monitoring at night  
5 was not done, so the glucose control was not good. Such an old child is really difficult  
6 to manage, half-sensible but not sensible."  
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### 12 **Excessive Financial Burden Theme**

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14 T1DM Caregiver Parents consistently reported the excessive financial burden of caring  
15 for a child with T1DM, including high cost of treatment. This burden was often cited  
16 as a factor for job and educational changes, affecting family member circumstances.  
17 Due to the long-term nature of treatment, medications and injection supplies are  
18 consumable items with sustained cost impact. Furthermore, caring for a young child  
19 with T1DM often requires care around the clock, with some parents reporting that one  
20 of the parents gave up employment, changed employment, or reduced hours to provide  
21 adequate care for their child, often decreasing household income and adding further  
22 financial stress to middle- and low-income families.  
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35 Interviewee DM2: "Using an insulin pump is a great economic pressure. It costs nearly  
36 20,000 CNY [about 3000 USD] a year. One tube is normally more than 110 CNY [about  
37 17 USD]. I will buy some during sales and let my friends buy some more from other  
38 channels. A tube can be used for three days. It costs nearly 20,000 CNY [about 3000  
39 USD] a year."  
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### 47 **Lack of Social Support Systems Theme**

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49 The lack of support system primarily includes limited social activities and insufficient  
50 social support system, as described below:  
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#### 53 **(1) Limited Social Activities**

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55 At present, the family structure in China is dominated by a typical nuclear family, and  
56 children are generally a primary focus of the family unit. Once a child is diagnosed with  
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3 T1DM, T1DM Caregiver Parents reported feeling disruption in the social activities of  
4 the family unit. In particular, mothers in the interview often left their employment,  
5 changed careers, or reduced hours to be able to care for their child with T1DM, thus  
6 narrowing their social circle to the immediate family members. This transition can  
7 result in social isolation and limit normal social activities of the parent.  
8  
9

10  
11 Interviewee DM10: "Since my child had a ketosis coma, I have never dared to relax  
12 again. I have lost myself. Every day in the year, there are no more visits to relatives or  
13 friends."  
14

## 15 (2) Insufficient Other Support Systems

16  
17 Insufficient systems of social support were a common concern of T1DM Caregiver  
18 Parents, especially those of children reaching school age and assuming autonomy over  
19 their care during school hours.  
20

21  
22 Interviewee DM12: "Unlike other countries, our children do not have diabetes nurses  
23 in school. When the child is at school, every time the teacher calls, I am terrified, always  
24 scared that something bad will happen. If the child's blood glucose is low, does the  
25 teacher know how to handle it? Will it be delayed?"  
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## 42 Discussion

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44 This study aimed to qualitatively examine perception of common challenges among  
45 parental caregivers of children with T1DM. Using Grounded Theory (GT), a method  
46 based in social science research, [20-21] the researchers examined and consolidated  
47 emergent themes from interview transcripts. In this study, parental caregivers of T1DM  
48 children consistently reported persistent psychological stress, changes in routine  
49 functions of the family unit, challenges in daily disease management for both the child  
50 and parental caregiver, financial strain, and disruption of social activities. Thus, this  
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3 qualitative study and the following sections aim to provide actionable insights for both  
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5 future research and patient support programs.  
6

### 7 **Reducing Persistent Psychological Strain in Parental Caregivers of Children with** 8 9 **T1DM Experience**

10  
11 This study showed that parental caregivers of children with T1DM were particularly  
12  
13 susceptible to psychological stress during the early stages after their child's first T1DM  
14  
15 diagnosis. These stressors manifested as recollections of negative emotions leading to  
16  
17 emotional distress, including shock, sadness, and anxiety. Further, repeat insulin  
18  
19 injections and finger blood glucose monitoring in child posed not only technical  
20  
21 challenges for non-medical professional caregivers, but also emotional distress in  
22  
23 parental caregivers. Shortly after a child's diagnosis, many parental caregivers reported  
24  
25 feelings of disbelief, resulting in catastrophic emotional disturbances linked to shock,  
26  
27 fear, frustration, despair, and sadness. These findings are consistent with other  
28  
29 quantitative psychological studies demonstrating posttraumatic stress disorder (PTSD)  
30  
31 symptoms in caregivers[20, 22-24]; however, the use of qualitative interview methods  
32  
33 enables additional insights into the character of reflective perceptions of parental  
34  
35 caregivers, and how such condition can be relieved. Our study suggests that the  
36  
37 emotional effects of "invisibility" of the T1DM prior to diagnosis can trigger guilt and  
38  
39 anxiety that exacerbate psychological stressors. Further, young age of the child and  
40  
41 uncertainty of social impact can also exacerbate the psychological effects on the  
42  
43 caregiver, leading to heightened anxiety and PTSD manifestations. In some cases, these  
44  
45 stressors can lead to catastrophic emotional experiences occurred in the early stage of  
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47 diagnosis and during a child's hospitalization, which is consistent with other  
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49 research[25].  
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58 In particular, following the hospital discharge of a child with T1DM, parental  
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3 caregivers in this study exhibited heightened emotions, characterized by poorly  
4 controlled worry, anxiety, sadness, stigma, annoyance, and guilt. During the course of  
5 our interviews, it emerged that worry, anxiety, and sorrow were closely linked to  
6 uncertainty of disease progression. This observation is consistent with prior studies that  
7 have shown parental caregivers of children with T1DM experience a heightened level  
8 of disease uncertainty compared to caregivers of other chronic states, which can exert  
9 adverse effects on the health and psychological condition of the parental caregivers and  
10 the children they care for[26]. Thus, medical staff should pay particular attention to  
11 these potential effects in parental caregivers.  
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23 Parental caregivers, in part due to their emotional bond with their child, are also affected  
24 emotionally by perceived stigma. Stigma refers to a kind of inner shame caused by  
25 illness that is viewed as a deficiency, which negatively affects patient psychology and  
26 can contribute noncompliance or delay of critical treatment and monitoring in  
27 T1DM[27]. During the interviews conducted in this study, some parents of children  
28 with T1DM expressed that diabetes would affect their child's future employment,  
29 marriage, and social standing, in some cases going so far as to hide their child's  
30 condition to avoid perceived discrimination. Stigma affects caregivers by playing on  
31 their guilt, which may be exacerbated by "causing" the child pain through blood tests  
32 and limiting activities or diet. Some parents also have limited scientific understanding  
33 of the illness, and perceive the disease to be a result of neglect in care that can further  
34 exacerbate feeling of guilt, anxiety, and depression. Parent's persistent emotional  
35 distress affects their own physical and mental health, thereby affecting management of  
36 blood glucose control in their children[28]. Thus, the emotional state of the parental  
37 caregiver is of concern to medical staff treating children with T1DM.  
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3 As prior research has shown, the self-efficacy of parental caregivers in diabetes  
4 management is related to the effectiveness of blood glucose control[29]. In the  
5 interviews conducted in this study, parental caregivers emphasized expectations placed  
6 on the mother's role, and their increased sense of self-efficacy. Parents that perceived  
7 themselves as competent in the role of caregiver consistency experienced less emotional  
8 distress. Through analyzing interviews, this study found that the psychological burden  
9 of parents primarily derives from the following courses: (1) Pressure of blood glucose  
10 management in children, especially in diet management; (2) Children's physical and  
11 mental pain caused by insulin injections, blood glucose monitoring, and diet restrictions;  
12 (3) Mood changes in children due to illness; and (4) The impact of the disease on the  
13 future of the children. These insights can be used to design integrated patient  
14 management programs that consider both parental caregiver emotional health and the  
15 medical condition of the T1DM child.  
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### 33 **Supporting the Transition of Parents into an Evolving Caregiver Role**

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35 Becoming a caregiver of child with T1DM is disruptive not only to the parent(s), but  
36 also to the family unit. Furthermore, the emotional burden on parental caregivers is  
37 increased by an evolving need for autonomy over T1DM care as children age. For  
38 younger children with T1DM, parental caregivers will need to dedicate substantial time  
39 and financial resources to their child's daily care, such as regular blood glucose  
40 measurement, injecting insulin, monitoring their diet and physical activities, and  
41 handling emergent issues. Common challenges in daily management include difficulty  
42 in blood glucose management, emotional management, parent-child conflict, and the  
43 transition from parental management to self-management. While technology has  
44 improved T1DM care through the use of insulin pumps and continuous blood glucose  
45 monitoring, often young children may not have access to these technologies or  
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3 compliance may not be possible[30]. These changes in activities of daily living in the  
4 family unit also impact relationships between parents and children, can lead to conflict.  
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6 Thus, additional support is needed in the community and clinical setting to support  
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Parental caregivers of children with T1DM also face challenges in transitioning their role to allow their child increased autonomy with age. In this study, it was apparent from interviews that, even at a young age, issues of the child's autonomy could affect the parent-child relationship and lead to family conflict. Previous studies have shown that families often experience conflicts in chronic disease care setting. In particular, children with T1DM and high levels of family conflict have been shown to have poorer blood glucose control and lower overall quality of life[31, 32]. As young children grow into adolescents, these conflicts may become more common or escalate. Khandan (2018)[33] found that when children with T1DM reached the age of 8 to 11, their parents begin to transfer diabetes management responsibility to them, gradually transitioning from "parental responsibility" to "cooperative support." While parents have a high degree of control over their young child's medical care, they may require outside support from clinicians or the community in transitioning these responsibilities as their child enters adolescents. Appropriate mental health and community support may thus improve outcomes among these children and their caregivers and help to achieve an effective transition to self-management as these children enter adolescence.

### **Improving Financial and Social Support Systems for Parental Caregivers of Children with T1DM in China**

In this study, parental caregivers of children with T1DM consistently reported a strain on household finances related to their child's care and disposable supplies, and a lack of social support. In the majority of cases, discussed in the present study, expenses were

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2  
3 covered by insurance only during hospital stay, but after discharge the expenses were  
4 paid by parents/guardians. Insulin medication was also partly covered by health  
5 insurance, but the reimbursement rate varied depending on the type of health insurance  
6 (up to 90%). Similar to the results of other studies[34], medications and disposable  
7 devices used for long-term treatment place a substantial and ongoing burden on these  
8 families, often affecting housing, employment, and economic opportunities for middle-  
9 and low-income families. Financial burden can affect the physical and mental health of  
10 parental caregivers, also limit or delay selection of treatment options that can influence  
11 the T1DM child's long-term prognosis.  
12  
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14 Furthermore, the lack of social support and relative social isolation of caregivers,  
15 particularly those that reduces hours or left jobs to act as primary caregivers (most  
16 common among mothers), was consistently reported in this study. The lack of support  
17 systems was apparent from limited family social activities, which often negatively  
18 impacted the parental caregiver's emotional state. Compared to other developed regions,  
19 China currently has a lack of diabetes nurses in kindergartens and primary or secondary  
20 schools. Thus, preschool and school-age children have to assume the responsibility of  
21 diabetes self-management during school hours. In addition, because of self-esteem  
22 issues or poor self-control, many parents in this study reported that blood sugar control  
23 was not ideal during school. Therefore, we propose that we should, as a healthcare  
24 system, selectively learn from the successful experience of other countries[35] and  
25 gradually implement training for school personnel and other personnel who come into  
26 contact with diabetic children to improve the social support system for children with  
27 diabetes.  
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30 Notably, this research is limited by the interpretation of the reviewers and coders. In  
31 particular, all interviewees and researchers were from a single hospital, which limits  
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3 the generalizability of the findings to a broader population. However, these insights  
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5 provide greater depth than mere quantitative characterizations, and may aid in  
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7 improving both psychological and physical outcomes of children with T1DM and their  
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9 parental caregivers.  
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## 14 **Conclusions**

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16  
17 Through a series of interviews that examined the perceptions of parental caregivers of  
18  
19 children with T1DM, this qualitative study employs grounded theory methods to  
20  
21 examine the emergent themes in these conversations, often anecdotally experiences by  
22  
23 health care professionals. This research gives voice to the common challenges faces by  
24  
25 parental caregivers as their young children are first diagnosed with T1DM and slowly  
26  
27 gain autonomy for their own chronic disease management with age. This research  
28  
29 demonstrated common themes of persistent psychological stress, difficulty managing  
30  
31 changes in family function, challenges in daily disease management, challenges of  
32  
33 excessive financial burden, and the impact of a lack of social support for parental  
34  
35 caregivers. By characterizing these common perceptions and experiences, we can better  
36  
37 prepare health care providers to support both the T1DM child and parental as they adapt  
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39 to medical management of T1DM at different life stages, thereby improving home self-  
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41 management capabilities.  
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## 51 **List of abbreviations**

52 T1DM: Type 1 Diabetes Mellitus

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54 QoL: Quality of life

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56  
57  
58 GT: Grounded Theory  
59  
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1  
2  
3 PTSD: posttraumatic stress disorder  
4

5 IRB: Institutional Review Board  
6

### 7 **Declarations**

8  
9  
10 **Funding:** This research received no specific grant from any funding agency in the  
11 public, commercial or not-for-profit sectors  
12

13 **Competing interests:** The authors declare no conflicts of interest in this study.  
14

15 **Authors' contributions:** The study was supervised by Dr. Ling Fan. The study was  
16 performed by Huijuan Tong. Data were coded and interpreted by Dr. Feng Qiu and Dr.  
17 Huijuan Tong. The manuscript was written by Huijuan Tong and Ling Fan.  
18

19 **Ethics approval and consent to participate:** This study was conducted in accordance  
20 with the Declaration of Helsinki and was approved by the Institutional Review Board  
21 (IRB) of Shengjing Hospital, China Medical University, Shenyang, China (Approval  
22 no. 2018PS362K). All participants provided written informed consent prior to  
23 participating in interviews.  
24

25 **Consent for publication:** Not applicable  
26

27 **Availability of data and materials:** The data set supporting the results of this article  
28 are included within the article. The datasets used and/or analysed during the current  
29 study are available from the corresponding author on reasonable request.  
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**Table 1 Semi-Structured Interview Outline for Parents of Children Aged  $\leq 14$  with Type 1 Diabetes Mellitus (T1DM Caregiving Parents)**

| Question # | Description  |
|------------|--|
| 1          | Could you please talk about the situation when your child was first diagnosed with type 1 diabetes and your reaction at that time?               |
| 2          | Could you please describe a day of caring for a child with type 1 diabetes?  |
| 3          | Since your child was diagnosed with diabetes, what has been your biggest concern, or what is the most difficult issue you have had to deal with? |
| 4          | How do you help your child manage his/her diet?  |
| 5          | How do you help your child manage his/her medication?  |
| 6          | How do you help your child manage his/her activities or exercise?  |
| 7          | How do you help your child manage his/her emotions?  |
| 8          | How do you manage your own life while taking care of your child?   |
| 9          | As a caregiver, what are your needs in caring for the child?   |
| 10         | Do you think you are qualified for the role of caring for a child with type 1 diabetes?  |

Note: This outline has been translated from the original Mandarin Chinese version. All interviews were conducted in the local language of the investigator (Mandarin Chinese).

**Table 2 Characteristics of Parental Caregivers of T1DM Children (T1DM Caregiver Parents) Interviewed**

| Characteristic                                  | Interviewee<br>(n = 20) |
|---|-------------------------|
| Children  |                         |
| Age (years), mean±SD                            | 10.6±2.45               |
| Onset age of T1DM, mean±SD                      | 7.2±2.4                 |
| Insulin regimen, n (%)                          |                         |
| Insulin pump use                                | 8 (40%)                 |
| Daily injections                                | 12 (60%)                |
| Gender, n(%)                                    |                         |
| Male  | 7 (35%)                 |
| Female  | 13 (65%)                |
| Parents   |                         |
| Age(year), mean±SD                              | 39.45±6.21              |
| Gender, n (%)                                   |                         |
| Male (self-identify as Father)                  | 8(40%)                  |
| Female (self-identify as Mother)                | 12(60%)                 |
| Current employment status, n (%)                |                         |
| Full-time                                       | 8 (40%)                 |
| Part-time                                       | 6 (30%)                 |
| Not working                                     | 6 (30%)                 |
| Highest education level, n (%)                  |                         |
| Junior high (middle) school or some high school | 6 (30%)                 |
| High school diploma                             | 6 (30%)                 |

|    |   |         |
|----|---|---------|
| 1  |   |         |
| 2  |   |         |
| 3  | Technical school (2-year degree or equivalent)  | 3 (15%) |
| 4  |   |         |
| 5  | Bachelor's degree (4-year degree or equivalent) | 5 (25%) |
| 6  |   |         |
| 7  |   |         |
| 8  | Monthly Income (CNY/USD), n (%)                 |         |
| 9  |   |         |
| 10 | < 3077/500                                      | 5 (25%) |
| 11 |   |         |
| 12 | 3077-11428/500-1700                             | 9 (45%) |
| 13 |   |         |
| 14 |   |         |
| 15 | >11428/1700                                     | 6 (30%) |
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For peer review only

**Table 3 Themes and Sub-themes Emerging from Interviews of Parental Caregivers of T1DM Children (T1DM Caregiver Parents)**

| <b>Themes</b>                   | <b>Subthemes</b>   |
|---------------------------------|--|
| Persistent psychological stress | (1) catastrophic emotional experience<br>(2) emotional distress based in negative emotions<br>(3) altered sense of self-efficacy<br>(4) perceived increased responsibility for parenting                         |
| Family function changes         | (1) changes in patterns of family life<br>(2) changes in parental roles and functions  |
| Challenges in daily management  | (1) technical difficulties managing blood glucose<br>(2) difficulties in emotional regulation and managing parent-child conflict<br>(3) transition from parental management to self-management as the child ages |
| Excessive financial burden      | (1) burden of disease treatment<br>(2) changes in economic sources   |
| Lack of social support system   | (1) limited social activities<br>(2) insufficient other support systems  |

# BMJ Open

## Characterizing Common Challenges Faced by Parental Caregivers of Children with Type 1 Diabetes Mellitus in Mainland China: A qualitative study

|                                 |   |
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| <b>Primary Subject Heading</b>: | Diabetes and endocrinology  |
| Secondary Subject Heading:      | Diabetes and endocrinology  |
| Keywords:                       | DIABETES & ENDOCRINOLOGY, General diabetes < DIABETES & ENDOCRINOLOGY, General endocrinology < DIABETES & ENDOCRINOLOGY   |
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3 **Characterizing Common Challenges Faced by Parental Caregivers of Children**  
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5 **with Type 1 Diabetes Mellitus in Mainland China: A qualitative study**  
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3 **1 Abstract**  
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5 **2 Objectives:** Mental state of parental caregiver affects outcomes in children with Type  
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8 **3 1 Diabetes Mellitus (T1DM).** This study aimed to qualitatively examine perception of  
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11 **4 common challenges among parental caregivers of children with T1DM.**

12 **5 Setting:** 45-60 minutes long semi-structured interviews were conducted with T1DM  
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15 **6 Parental Caregivers.** Interview recordings were transcribed and coded in NVivo 11.0  
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17 **7 to observe emergent themes.**

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19 **8 Participants:** Eligible T1DM Caregiving Parents (parent(s) and/or legal guardian(s))  
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22 **9 were identified from caregivers attending visits with children hospitalized or assessed**  
23  
24 **10 in the Pediatric Neuroendocrinology Department of Shengjing Hospital, China**  
25  
26 **11 Medical University in Shenyang from January 2018 to June 2019.**

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28 **12 Primary and secondary outcome measures:** Not applicable.

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30 **13 Results:** A total of 20 T1DM Caregiving Parents were interviewed, aged 30 to 53  
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33 **14 years, including 7 fathers and 13 mothers, with their children mean age of 10.6±2.45**  
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35 **15 years.** Content analysis revealed 5 major themes with 13 subthemes, including  
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38 **16 persistent psychological stress (catastrophic emotions, emotional distress, and altered**  
39  
40 **17 self-efficacy), family function change (altered family life patterns and changes in**  
41  
42 **18 parental role/function), challenges in daily management (technical challenges,**  
43  
44 **19 emotional regulation, parent-child conflict, and transition of care autonomy from**  
45  
46 **20 parent to child), financial burden (cost burden of treatment and altered family**  
47  
48 **21 economics), and lack of social support (social activity limitations and insufficient**  
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50 **22 support system).**

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53 **23 Conclusions:** Period of emotional disturbance during initial diagnosis, psychological  
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56 **24 stresses of long-term caregiving, and conflict emerging from transition from parental**  
57  
58 **25 to child responsibility all can cause psychological response detrimental to parental**  
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26 caregivers and T1DM children. This work provides compelling evidence for the role  
27 of assessment and intervention in parental caregiver psychological and emotional  
28 wellbeing in diabetes care, as well as for the necessity of improved social and school  
29 support for children with T1DM in China.

30

31 **Keywords:** Type 1 Diabetes Mellitus, Grounded Theory, Qualitative Methods,  
32 Caregiving, Diabetes Care, Psychological Perceptions

33

#### 34 **Strengths and limitations of this study**

35 **1.** This is the first qualitative study, which describes the conditions and  
36 consequences of young children with T1DM relying on parental caregivers for disease  
37 management in China.

38 **2.** Each interview performed in this study took 45-60 minutes, with structure based  
39 on the theory of individual and family self-management, and formulated through  
40 expert evaluation of the research purpose, population, and existent body of literature.

41 **3.** To provide compelling evidence, heuristic content analysis was performed using  
42 grounded theory methods in order to summarize text data, and identify and refine  
43 emergent themes.

44 **4.** This study is limited by the interpretation of the reviewers and coders.

45 **5.** This is a single-center study, with limited generalizability of the findings, and a  
46 further multicenter study was needed.

#### 47 **Introduction**

48 Type 1 Diabetes Mellitus (T1DM) is a common enough chronic disease in children,  
49 and both the parental caregiver and the child diagnosed with T1DM must learn how to  
50 manage the disease associated tasks, with underlying financial, emotional, and social

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2  
3 51 impact on the family unit<sup>[1]</sup>. With the incidence of T1DM increasing by 2% to 5%  
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5 52 each year worldwide<sup>[2]</sup>, an increasing number of families with young children are  
6  
7 53 influenced by its burden. Although the incidence of T1DM in China is lower than that  
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9 54 in Europe or the United States, being currently 5.6 per 100,000 live births<sup>[3]</sup>, China  
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11 55 ranks fourth in the world for T1DM occurrence — and the number of cases is  
12  
13 56 increasing each year<sup>[4]</sup>. In addition, rural communities in China generally have fewer  
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15 57 resources and growing number of T1DM cases outside of urban centers would  
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17 58 eventually increase the strain on Chinese parental caregivers. Thus, examining the  
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19 59 situation of middle- and low-income parents of children with T1DM in China is  
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21 60 essential to improve T1DM care and long-term outcomes.  
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26 61 Management of T1DM in children involves changes in daily living activities that  
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28 62 affect not only the child receiving care but also the caregiver. That includes  
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30 63 continuous glucose monitoring (4 or more times per day), ensuring insulin injections  
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32 64 via insulin pump or injecting insulin multiple times a day, tracking and calculating  
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34 65 daily carbohydrate intake as well as physical activity levels important to prevention of  
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36 66 hypoglycemic and hyperglycemic episodes<sup>[5-6]</sup>. Majority of children with T1DM  
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38 67 under age of 13 are unable to self-manage their T1DM care, and instead rely heavily  
39  
40 68 on their parental caregiver for disease management<sup>[7]</sup>. Treatment for children with  
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42 69 T1DM is aimed at ensuring stable blood glucose levels, minimizing occurrence of  
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44 70 potentially severe hypoglycemic events, and preventing long-term complications of  
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46 71 diabetes as the child grows<sup>[8]</sup>. These responsibilities presumably place immense  
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48 72 psychological and financial stress on parental caregivers.  
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53 73 Owing to the relatively lower incidence of T1DM outside of urban centers in China,  
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55 74 the emotional toll, financial burden, and social isolation experienced by parental  
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57 75 caregivers of young children with T1DM can be immense. Despite improvements in  
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3 76 T1DM medications and treatment technologies, many children still experience  
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5 77 adverse health effects due to invasive procedures or ineffective blood glucose  
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7 78 control<sup>[9]</sup>; more than 58.6% of children with T1DM in China do not achieve sustained  
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9 79 hemoglobin control (glycosylated hemoglobin lower than 7.5%)<sup>[10]</sup>, which leads to  
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11 80 complications, that have adverse impact on the child's growth and long-term health,  
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13 81 and place significant burden on caregivers and the family unit. This justifies a  
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15 82 necessity to study T1DM care and its impact on parental caregivers through a social  
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17 83 lens.

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19  
20  
21 84 Previously Rankin et al. (2018)<sup>[11]</sup> used qualitative methods to examine the strategies  
22  
23 85 and motivations of children with T1DM and their caregivers, providing insights into  
24  
25 86 how diabetes management can be improved. Other researchers have also  
26  
27 87 demonstrated that successful disease management of children with T1DM not only  
28  
29 88 requires the children to manage their individual health, but also requires their  
30  
31 89 cooperation with caregivers who share the responsibility for the child's medical  
32  
33 90 management<sup>[11]</sup>. These burdens can, however, result in caregiving parents of children  
34  
35 91 with T1DM feeling isolated and helpless when faced with the challenges of chronic  
36  
37 92 disease management. Psychologically, caregivers may manifest a sense of self-doubt,  
38  
39 93 guilt, or anxiety, and many of them experience traumatic initial confusion as they try  
40  
41 94 to integrate these new responsibilities into their family's routine when their child is  
42  
43 95 first diagnosed<sup>[12]</sup>. These feelings may be transient or persistent, and exacerbate if a  
44  
45 96 child experiences hypoglycemic events or other emergency situations that contributes  
46  
47 97 to caregiver trauma and anxiety<sup>[13-15]</sup>. Understanding the experiences of parental  
48  
49 98 caregivers of children with T1DM could greatly improve clinical and social  
50  
51 99 interventions, help parents adapt to the role of caregiver, and achieve optimal health  
52  
53 100 outcomes for T1DM children. However, current research on the topic in China is  
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2  
3 101 primarily limited to quantitative studies on the quality of life (QoL)<sup>[15]</sup>, psychological  
4  
5 102 state<sup>[16]</sup> and coping style of the children or their parents<sup>[17]</sup>.  
6  
7  
8 103 Qualitative research methodologies can provide actionable insights into the  
9  
10 104 psychological state, behaviors, and motivations of patients and caregivers who  
11  
12 105 manage T1DM<sup>1</sup>. This study employs qualitative methods to examine the perceptions  
13  
14 106 of parental caregivers of young children (aged 14 or younger) with T1DM in China,  
15  
16 107 their key challenges as caregivers during transition from full management of young  
17  
18 108 children with T1DM to an older child with increasing autonomy over his or her  
19  
20 109 medical care. Thus, present research is designed to provide actionable insights for  
21  
22 110 improving social support and management of these patients, in a holistic context that  
23  
24 111 considers the parental caregiver and family unit.  
25  
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## 31 **Methods**

### 32 **Patient and Public Involvement**

33  
34 114 Patients or the public were not involved in the design, or conduct, or reporting, or  
35  
36 115 dissemination plans of our research.  
37  
38  
39

### 40 **Study Population and Design**

41  
42 118 Qualitative research methods were employed to examine social, emotional, and  
43  
44 119 experiential perceptions of parent(s) and/or legal guardian(s) of children diagnosed  
45  
46 120 with T1DM, referred to as T1DM Caregiving Parent for purposes of this article.  
47  
48 121 Synchronous, in-person, semi-structured interviews were conducted to collect  
49  
50 122 qualitative data, and emergent heuristic content analysis was subsequently performed  
51  
52 123 on transcripts. Eligible T1DM Caregiving Parents were identified from caregivers  
53  
54 124 attending visits with children hospitalized or assessed in the Pediatric  
55  
56 125 Neuroendocrinology Department of Shengjing Hospital, China Medical University in  
57  
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1  
2  
3 126 Shenyang from January 2018 to June 2019.

4  
5 127 To be eligible for participation in study interview, T1DM Caregiving Parents were  
6  
7  
8 128 required to (1) be the parent and/or legal guardian of a child 14 years of age or  
9  
10 129 younger with diagnosed T1DM, and (2) be a primary caregiver during at least 6  
11  
12 130 months of continuous care for child being treated for T1DM during this period<sup>[18]</sup>  
13  
14 131 T1DM Caregiving Parents were considered ineligible to participate in interviews if  
15  
16 132 (1) the child with T1DM also experienced other significant comorbidities or chronic  
17  
18 133 diseases; (2) the child with T1DM was considered to require immediate medical care  
19  
20 134 or treatment and the study could pose an undue burden on the patient or caregiver; (3)  
21  
22 135 T1DM Caregiving Parent was unable to communicate fluently in the local language of  
23  
24 136 the investigator (Mandarin Chinese).

25  
26  
27  
28 137 This study was conducted in accordance with the Declaration of Helsinki and was  
29  
30 138 approved by the Institutional Review Board (IRB) of Shengjing Hospital, China  
31  
32 139 Medical University, Shenyang, China (Approval no. 2018PS362K). All participants  
33  
34 140 provided written informed consent prior to participating in interviews.

### 35 36 37 141 **Sampling Methods and Process**

38  
39 142 Purposive nonprobability sampling was used, in which eligible T1DM Caregiving  
40  
41 143 Parents were approached for participation as they visited clinic. To ensure a  
42  
43 144 representative sample, the heterogeneity of sample selection was expanded for T1DM  
44  
45 145 Caregiving Parent age, marital status, education level, and T1DM child age and  
46  
47 146 disease course. The study was discontinued when qualitative data reached saturation,  
48  
49 147 which was expected to occur between 15 and 20 interviews, as previously described<sup>[19]</sup>  
50  
51 148 <sup>20]</sup> When the number of interviews reached 20, the data in our research was saturated,  
52  
53 149 and no new information was obtained, so sampling was terminated.

### 54 55 56 57 150 **Data Collection**

1  
2  
3 151 An IRB-approved semi-structured interview outline was used to ensure consistency  
4  
5 152 while performing interviews. The interview structure was based on the theory of  
6  
7 153 individual and family self-management<sup>[21]</sup>, and formulated through expert evaluation  
8  
9 154 of the research purpose, population, and existent body of literature. The outline used  
10  
11 155 in interviews is shown in **Table 1**. The planned duration of the interview was 45 to 60  
12  
13 156 minutes.

14  
15  
16  
17 157 Upon arrival at the clinical site, the head nurse of the clinical unit familiar with the  
18  
19 158 T1DM Caregiving Parent met the interviewee, led them to the interview site, and  
20  
21 159 made introductions. Prior to the start of the interview, the interviewer explained the  
22  
23 160 purpose, significance, methods, rights of the interviewee, and privacy protection  
24  
25 161 measures. Written informed consent was then obtained before starting each interview.  
26  
27 162 The interview location was selected as audio visual classroom located in the Pediatric  
28  
29 163 Neuroendocrinology Ward. This location was selected for the quiet environment, free  
30  
31 164 of distractions. Interviews were conducted by the authors, who were provided with  
32  
33 165 training on semi-structured interviews and use of neutral, objective, and non-leading  
34  
35 166 language during the interview to maximize data integrity.

### 36 37 38 39 40 167 **Data Transcription and Coding**

41  
42 168 Each interview was recorded using audio recording devices, and digitally transcribed  
43  
44 169 asynchronously (with 48 hours after each interview) by the researchers. Transcripts  
45  
46 170 were recorded in MS Word (Microsoft, USA), and verified by a second researcher. To  
47  
48 171 ensure data integrity, interviewees were provided with a copy of their interview  
49  
50 172 transcript and allowed to suggest corrections, which, if appropriate, were assessed and  
51  
52 173 integrated by the researchers upon review of the original recording.  
53  
54 174 Heuristic coding was performed using emergent grounded theory methods<sup>[20]</sup>  
55  
56 175 manually using transcripts imported into NVivo 11.0 (QSR International, USA) using  
57  
58  
59  
60

1  
2  
3 176 manual code to summarize text data, and identify and refine themes. Coding was  
4  
5 177 verified by a second researcher, the numbers were used to identify the interviewees in  
6  
7  
8 178 place of their real names, DM1-DM20. Emergent themes and subthemes were  
9  
10 179 identified using a grounded theory approach.

## 11 12 180 **Data Analysis and Reporting**

13  
14  
15 181 Textual coding results in NVivo 11.0 were reported as counts and percentages (data  
16  
17 182 not shown) and themes/sub-themes were presented descriptively using qualitative  
18  
19 183 analysis methods. All analyses were performed in the local language of the interview  
20  
21 184 conduct (Mandarin Chinese), and the data were analyzed and collected  
22  
23  
24 185 simultaneously. The theme of the interviews was extracted using content analysis  
25  
26 186 methodology by way of three-grade coding. Final results were translated to English,  
27  
28 187 and all translations were performed by the researchers to ensure integrity of  
29  
30  
31 188 translations.

## 32 33 34 35 190 **Results**

### 36 37 191 **Participant Characteristics**

38  
39  
40 192 Saturation was reached when 20 T1DM Caregiving Parents (N = 20) completed  
41  
42 193 interviews. Interviewed T1DM Caregiving Parents included 7 fathers and 13 mothers  
43  
44 194 (gender roles were self-identified by the interviewee), aged 30 to 53 years, with their  
45  
46  
47 195 children mean age of  $10.6 \pm 2.45$  years. Of these patients, 8 were caregivers of children  
48  
49 196 with T1DM that were treated with insulin pumps, and 12 were caregivers of children  
50  
51 197 with T1DM that were treated with subcutaneous injections. Socio-demographic  
52  
53 198 information for T1DM Caregiving Parents completing interviews and demographic  
54  
55 199 and clinical condition of their children are summarized in **Table 2**.

56  
57  
58 200 By analyzing the transcripts of interviews, five major emergent themes were observed  
59  
60



1  
2  
3 201 consistently throughout the interview data: (1) persistent psychological stress; (2)  
4  
5 202 family function changes; (3) challenges in daily management; (4) excessive economic  
6  
7  
8 203 burden; (5) lack of support system. All 13 minor subthemes within these 5 themes, are  
9  
10 204 summarized in **Table 3**. The themes/sub-themes are further characterized below.

### 12 205 **Theme of Persistent Psychological Stress**

14 206 Persistent psychological stress was identified as prominent theme across interviews,  
15  
16  
17 207 with four key sub-themes emerging from coding:

#### 19 208 **(1) Catastrophic Emotional Experience**

21 209 In acute period following diagnosis, parents often experienced emotions that can be  
22  
23  
24 210 described as catastrophic, including shock, fearfulness, frustration, hopelessness,  
25  
26 211 sadness, and feelings that disaster is imminent.

28 212 Interviewee DM2: "When the doctor told me that my child was diabetic, I felt like [I  
29  
30 213 was] struck by lightning and the sky was falling. My child's life is basically over."

#### 33 214 **(2) Emotional Distress Based in Negative Emotions**

35 215 Negative emotions observed in T1DM Caregiver Parents primarily included continual  
36  
37 216 worry, anxiety, sadness, stigma, annoyance, and guilt. Worry was embodied in  
38  
39  
40 217 anxiety and sadness, often with connections to the uncertainty of disease progression  
41  
42 218 in their child. Some parents also experienced symptoms of worry and invasive  
43  
44 219 thoughts about the potential for their children to be discriminated in the future  
45  
46 220 because of their illness, leading some to even report hiding their child's illness in  
47  
48 221 common social contexts. Further, parents reported feeling guilt linked to social  
49  
50  
51 222 isolation and dietary restrictions experienced by their child, etiology of illness (often  
52  
53 223 linked to limited clinical understanding of T1DM), or feeling of being "at fault" for  
54  
55 224 their child's condition.

57  
58 225 Interviewee DM2: "It's still like a sword hanging over my head. I don't know when  
59  
60

1  
2  
3 226 the complications will come. I live with fear every day."  
4

5 227 Interviewee DM6: I don't want people around to know that my child has diabetes.  
6

7 228 Diabetes is an undead cancer. Thinking about it in another way, who wants his child  
8

9 229 to marry a diabetic in the future? You may only have to marry someone who also has  
10

11 230 diabetes. My child doesn't want her classmates to know that she is different from  
12

13 231 others."  
14

15 232 Interviewee DM3: "My thoughts are that he is too young and suffers too much. He  
16

17 233 has to get injections and blood tests every day, and his fingers are pierced constantly.  
18

19 234 As a parent, I feel like a failure. I have not taken good care of my child and have been  
20

21 235 busy with work. I feel like I neglect taking care of him."  
22

### 23 236 **(3) Altered Sense of Self-Efficacy**

24 237 T1DM Caregiver Parents also showed self-doubt owing to lack of experience in  
25

26 238 chronic disease care. In the most extreme cases, these feelings manifest as a severe  
27

28 239 lack of self-compassion, wherein parents expressed doubt in their ability to  
29

30 240 competently care for their child.  
31

32 241 Interviewee DM6: "Taking care of [my daughter], it's not that I think I can or can't,  
33

34 242 but that I must be able to do. It's like a parent's obligation. If I can't, what else can  
35

36 243 she do? It's not something I can or can't do. It's something I must be able to do."  
37

### 38 244 **(4) Perceived Increased Responsibility for Parenting**

39 245 T1DM Caregiver Parents reported perceiving a heavier burden of responsibility to  
40

41 246 manage their child's disease and remain hypervigilant, in particular for young  
42

43 247 children with T1DM not capable of self-managing. Parents perceive that, compared to  
44

45 248 children without T1DM, both parents and children bore additional responsibilities.  
46

47 249 Interviewee DM19: "Now our child is too young to take care of herself. As parents,  
48

49 250 we are duty-bound, we have to be good supervisors. We supervise our child's diet,  
50  
51  
52  
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3 251 exercise, blood glucose testing and injections. Although we are not professionals, we  
4  
5 252 will be dedicated to protecting our child's health. "

### 8 253 **Altered Facility Function**

9  
10 254 Changes in family life included two prominent subthemes:

#### 12 255 **(1) Changes in Patterns of Family Life**

14 256 Changes in routine patterns of daily living within the family unit were consistently  
15  
16  
17 257 reported by T1DM Caregiver Parents. These changes included changes in family  
18  
19 258 activities designed to assist children in adapting to their life after T1DM diagnosis. On  
20  
21 259 one hand, parents reported striving to retain normalcy for their children; however, the  
22  
23 260 child's T1DM was also often reported to be disruptive to others, particularly other  
24  
25 261 children, in the family unit. Parents also reported aiming to incorporate blood glucose  
26  
27 262 measurement in routine daily living activities of the family unit, with mixed success.

28  
29 263 Interviewee DM16: "It is inevitable that [when living with a child with T1DM] you  
30  
31 264 can't be the same as other families. We have to consider our child's physical strength  
32  
33 265 and whether [he] can eat regularly. Especially when faced with a table full of good  
34  
35 266 food, it is uncomfortable for the child to see others eating."

36  
37 267 Interviewee DM18: "Now we guide our child to think that measuring blood glucose  
38  
39 268 and injecting insulin is a routine in life, just like showers before bed. We don't want  
40  
41 269 our child to feel that injecting insulin before meals is a burden."

#### 43 270 **(2) Changes in Parental Role and Function**

44  
45 271 T1DM Caregiver Parents consistently reported that they perceived differences  
46  
47 272 between their "normal" role and function compared with their prior lifestyle before  
48  
49 273 their child's diagnosis. Specifically, T1DM Caregiver Parents expressed that their  
50  
51 274 child's diagnosis affected their future career planning, life focus, and goals, and often  
52  
53 275 resulting in a greater amount of time spent tending medical needs of their child.  
54  
55  
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1  
2  
3 276 Interviewee DM5: "Now I rarely focus my energy on the company [I work for], just  
4  
5 277 get off work as soon as possible. I used to leave early and return late to make money.  
6  
7  
8 278 Now I quit my job and found a new one that can make a living while taking care of  
9  
10 279 my child. When she is on vacation, so am I."

11  
12 280 In some cases significant housing and job/school changes are made to accommodate  
13  
14 281 the child's T1DM care.

15  
16  
17 282 Interviewee DM14: "My family is in the countryside, but our child comes to a school  
18  
19 283 in the city. Since our child has the disease, diabetes, and cannot live in school, I have  
20  
21 284 to accompany him to study. My child and I rented a house near the school, which is  
22  
23  
24 285 convenient for me to take care of him, and we will return to the countryside during  
25  
26 286 vacation, where his father works.

### 27 287 **Challenges in Daily Management Theme**

28  
29  
30 288 Challenges in daily management were consistency reported by T1DM Caregiver  
31  
32  
33 289 Parents, including:

#### 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60

#### 39 290 **(1) Technical Difficulties in Blood Glucose Management**

40 291 T1DM Caregiver Parents reported technical difficulties in blood glucose management,  
41  
42 292 including unsatisfactory or irregular blood glucose levels, primarily associated with  
43  
44 293 dietary control, exercise compliance, untimely blood glucose monitoring, and insulin  
45  
46 294 injection dosage adjustment. Parents expressed that lack of self-management, often  
47  
48 295 owing to social and educational obligations, was often a key concern.

49 296 Interviewee DM3: "He is in the second grade of junior high school. There is a lot of  
50  
51 297 tutoring outside school. He has to get up at 5:30 in the morning to study and finish  
52  
53 298 school at 5:30 in the evening. If goes to the tutoring class, he returns at 8:30. There is  
54  
55 299 no time to exercise. At school, his blood glucose control was poor [but] it is  
56  
57 300 impossible to ask him to leave school to take measurements before and after meals."

## 301 (2) Emotional Regulation and Managing Parent-Child Conflict

302 In addition to the regulation of T1DM Caregiver Parents' own emotions, interviewees  
303 also reported difficulty in assessing and managing their child's emotional and  
304 psychological needs.

305 Interviewee DM14: "[My daughter with T1DM] feels that if her classmates know she  
306 is sick and can't be cured, she will be inferior to others. Often it was lunch at noon,  
307 and she went to the toilet to get an injection, because she is afraid of being  
308 discriminated against by her classmates or something. Our child's self-esteem is  
309 strong, so she ran to the toilet for injections; at that time, if another child went to the  
310 toilet, she would be frightened, remove the needle and hurriedly put it away. She  
311 would not press and was still bleeding. As a parent, I feel distressed, but I don't know  
312 how to help the child to feel better." Interviewees consistently reported that  
313 parent-child conflict stemmed from inability to communicate effectively and  
314 perception of their children's poor compliance with disease management. As children  
315 age and their sense of autonomy increases, parents reported difficulty in transitioning  
316 to stages where their child exerts greater autonomy over their T1DM care and  
317 monitoring. In particular, interviewees reported resistance from their child, and  
318 perceptions that the child felt controlled by the parent's actions.

319 Interviewee DM20: "I understand that the child is also upset and there is no place to  
320 vent. I restrict her diet and control her blood glucose measurements. How can she not  
321 resist psychologically? I feel that I can't get into her heart, I don't know how to get  
322 along with her."

## 323 (3) Transition from Parental Management to Self-Management as the Child 324 Ages

325 With changes in their child's growth and developmental stage, the roles and function

1  
2  
3 326 of children and parents in T1DM management shifts. However, premature transfer of  
4  
5 327 diabetes management tasks to children with T1DM is now considered a factor leading  
6  
7  
8 328 to poor blood glucose control. Many T1DM Caregiver Parents expressed uncertainty  
9  
10 329 or frustration on transition timing.

11  
12 330 Interviewee DM15: "In the first year, we helped her with her insulin injections, and  
13  
14 331 then she did it by herself for the next two years. The blood glucose monitoring at  
15  
16  
17 332 night was not done, so the glucose control was not good. Such an old child is really  
18  
19 333 difficult to manage, half-sensible but not sensible."

#### 21 334 **Excessive Financial Burden Theme**

22  
23  
24 335 T1DM Caregiver Parents consistently reported the excessive financial burden of  
25  
26 336 caring for a child with T1DM, including high cost of treatment. This burden was often  
27  
28 337 cited as a factor for job and educational changes, affecting family member  
29  
30 338 circumstances. Due to the long-term nature of treatment, medications and injection  
31  
32 339 supplies are consumable items with sustained cost impact. Furthermore, caring for a  
33  
34 340 young child with T1DM often requires care around the clock, with some parents  
35  
36 341 reporting that one of the parents gave up employment, changed employment, or  
37  
38 342 reduced hours to provide adequate care for their child, often decreasing household  
39  
40 343 income and adding further financial stress to middle- and low-income families.

41  
42  
43 344 Interviewee DM2: "Using an insulin pump is a great economic pressure. It costs  
44  
45 345 nearly 20,000 CNY [about 3000 USD] a year. One tube is normally more than 110  
46  
47 346 CNY [about 17 USD]. I will buy some during sales and let my friends buy some more  
48  
49 347 from other channels. A tube can be used for three days. It costs nearly 20,000 CNY  
50  
51 348 [about 3000 USD] a year."

#### 52 349 **Lack of Social Support Systems Theme**

53  
54  
55 350 The lack of support system primarily includes limited social activities and insufficient  
56  
57  
58  
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60

1  
2  
3 351 social support system, as described below:  
4

5 352 **(1) Limited Social Activities**  
6

7  
8 353 At present, the family structure in China is dominated by a typical nuclear family, and  
9  
10 354 children are generally a primary focus of the family unit. Once a child is diagnosed  
11  
12 355 with T1DM, T1DM Caregiver Parents reported feeling disruption in the social  
13  
14 356 activities of the family unit. In particular, mothers in the interview often left their  
15  
16 357 employment, changed careers, or reduced hours to be able to care for their child with  
17  
18 358 T1DM, thus narrowing their social circle to the immediate family members. This  
19  
20 359 transition can result in social isolation and limit normal social activities of the parent.  
21  
22

23  
24 360 Interviewee DM10: "Since my child had a ketosis coma, I have never dared to relax  
25  
26 361 again. I have lost myself. Every day in the year, there are no more visits to relatives or  
27  
28 362 friends."  
29

30 363 **(2) Insufficient Other Support Systems**  
31

32  
33 364 Insufficient systems of social support were a common concern of T1DM Caregiver  
34  
35 365 Parents, especially those of children reaching school age and assuming autonomy over  
36  
37 366 their care during school hours.  
38

39  
40 367 Interviewee DM12: "Unlike other countries, our children do not have diabetes nurses  
41  
42 368 in school. When the child is at school, every time the teacher calls, I am terrified,  
43  
44 369 always scared that something bad will happen. If the child's blood glucose is low,  
45  
46 370 does the teacher know how to handle it? Will it be delayed?"  
47

48  
49 371  
50

51 372 **Discussion**  
52

53  
54 373 This study aimed to qualitatively examine perception of common challenges among  
55  
56 374 parental caregivers of children with T1DM. Using Grounded Theory (GT), a method  
57  
58 375 based in social science research <sup>[20-21]</sup>, researchers examined and consolidated  
59  
60

1  
2  
3 376 emergent themes from interview transcripts. In this study, parental caregivers of  
4  
5 377 T1DM children consistently reported persistent psychological stress, changes in  
6  
7 378 routine functions of the family unit, challenges in daily disease management for both  
8  
9 379 the child and parental caregiver, financial strain, and disruption of social activities.  
10  
11 380 Thus, this qualitative study and the following sections aim to provide actionable  
12  
13 381 insights for both future research and patient support programs.  
14  
15  
16

### 17 382 **Reducing Persistent Psychological Strain in Parental Caregivers of Children** 18 19 383 **with T1DM Experience**

20  
21 384 This study showed that parental caregivers of children with T1DM were particularly  
22  
23 385 susceptible to psychological stress during the early stages after their child's first  
24  
25 386 T1DM diagnosis. These stressors manifested as recollections of negative emotions  
26  
27 387 leading to emotional distress, including shock, sadness, and anxiety. Further, repeat  
28  
29 388 insulin injections and finger blood glucose monitoring in child posed not only  
30  
31 389 technical challenges for non-medical professional caregivers, but also emotional  
32  
33 390 distress in parental caregivers. Shortly after a child's diagnosis, many parental  
34  
35 391 caregivers reported feelings of disbelief, resulting in catastrophic emotional  
36  
37 392 disturbances linked to shock, fear, frustration, despair, and sadness. These findings are  
38  
39 393 consistent with other quantitative psychological studies demonstrating posttraumatic  
40  
41 394 stress disorder (PTSD) symptoms in caregivers<sup>[20 22-24]</sup>; however, the use of qualitative  
42  
43 395 interview methods enables additional insights into the character of reflective  
44  
45 396 perceptions of parental caregivers, and how such condition can be relieved. Our study  
46  
47 397 suggests that the emotional effects of "invisibility" of the T1DM prior to diagnosis  
48  
49 398 can trigger guilt and anxiety that exacerbate psychological stressors. Further, young  
50  
51 399 age of the child and uncertainty of social impact can also increase psychological  
52  
53 400 pressure on the caregiver, leading to anxiety and PTSD manifestations. In some cases,  
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1  
2  
3 401 these stressors can lead to catastrophic emotional experiences occurred in the early  
4  
5 402 stage of diagnosis and during a child's hospitalization, which is consistent with other  
6  
7  
8 403 research<sup>[25]</sup>.

9  
10 404 In particular, following the hospital discharge of a child with T1DM, parental  
11  
12 405 caregivers in this study noted a variety of negative emotions, in particular poorly  
13  
14 406 controlled worry, anxiety, sadness, stigma, annoyance, and guilt. During the course of  
15  
16  
17 407 our interviews, it was found that worry, anxiety, and sorrow were closely linked to  
18  
19 408 uncertainty of disease progression. This observation is consistent with prior studies  
20  
21 409 that have shown parental caregivers of children with T1DM experience a heightened  
22  
23 410 level of disease uncertainty compared to caregivers of other chronic states, which can  
24  
25  
26 411 exert adverse effects on the health and psychological condition of the parental  
27  
28 412 caregivers and the children they care for<sup>[26]</sup>. Thus, medical staff should pay particular  
29  
30 413 attention to these potential effects in early stages of the disease progression.

31  
32  
33 414 Parental caregivers, in part due to their emotional bond with their child, are also  
34  
35 415 affected emotionally by perceived stigma. Stigma refers to a kind of inner shame  
36  
37 416 caused by illness that is viewed as a deficiency, which negatively affects patient  
38  
39 417 psychology and can contribute to noncompliance or delay of critical treatment and  
40  
41  
42 418 monitoring in T1DM<sup>[27]</sup>. During the interviews conducted in this study, some parents  
43  
44 419 of children with T1DM expressed that diabetes would affect their child's future  
45  
46 420 employment, marriage, and social standing, in some cases going so far as to hide their  
47  
48 421 child's condition to avoid perceived discrimination. Stigma affects caregivers by  
49  
50 422 playing on their guilt, which may be exacerbated by "causing" pain to the child  
51  
52 423 through blood tests and limiting activities or diet. Some parents also have limited  
53  
54 424 scientific understanding of the illness, and perceive the disease to be a result of  
55  
56 425 neglect in care that can further exacerbate feeling of guilt, anxiety, and depression.  
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3 426 Parent's persistent emotional distress affects their own physical and mental health,  
4  
5 427 thereby affecting management of blood glucose control in their children<sup>[28]</sup>. Thus,  
6  
7 428 whether or not parental caregiver have let the stigma to influence their emotional state  
8  
9 429 concerns medical staff, related to the treatment of children with T1DM.

10  
11  
12 430 As prior research has shown, the self-efficacy of parental caregivers in diabetes  
13  
14 431 management is related to the effectiveness of blood glucose control<sup>[29]</sup>. In the  
15  
16 432 interviews conducted during this study, parental caregivers emphasized expectations  
17  
18 433 placed on the mother's role, and their increased sense of self-efficacy. Parents that  
19  
20 434 perceived themselves as competent in the role of caregiver consistency experienced  
21  
22 435 less emotional distress. Through analyzing interviews, this study found that the  
23  
24 436 psychological burden of parents primarily derives from the following courses: (1)  
25  
26 437 Pressure of blood glucose management in children, especially in diet management; (2)  
27  
28 438 Children's physical and mental pain caused by insulin injections, blood glucose  
29  
30 439 monitoring, and diet restrictions; (3) Mood changes in children due to illness; and (4)  
31  
32 440 The impact of the disease on the children's future. These insights can be used to  
33  
34 441 design integrated patient management programs that consider both parental caregiver  
35  
36 442 emotional health and the medical condition of the T1DM child.

### 443 **Supporting the Transition of Parents into an Evolving Caregiver Role**

444 Becoming a caregiver of child with T1DM is disruptive not only to the parent(s), but  
45  
46 445 also to the family unit. Furthermore, the emotional burden on parental caregivers is  
47  
48 446 increased by an evolving need for autonomy over T1DM care as children age. For  
49  
50 447 younger children with T1DM, parental caregivers will need to dedicate substantial  
51  
52 448 time and financial resources to their child's daily care, such as regular blood glucose  
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54 449 measurement, injecting insulin, monitoring their diet and physical activities, and  
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56 450 handling emergent issues. Common challenges in daily management include difficulty  
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3 451 in blood glucose management, emotional management, parent-child conflict, and the  
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5 452 transition from parental management to self-management. While technology has  
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7 453 improved T1DM care through the use of insulin pumps and continuous blood glucose  
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9 454 monitoring, often young children may not have access to these technologies or  
10  
11 455 compliance may not be possible<sup>[30]</sup>. These changes in activities of daily living in the  
12  
13 456 family unit also impact relationship between parents and children, leading to conflict.  
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15 457 Thus, additional care is needed in the community and clinical setting to support  
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17 458 parents transitioning through the various stages of T1DM caregiver roles.  
18  
19 459 Parental caregivers of children with T1DM also face challenges in transitioning their  
20  
21 460 role to manage their child increased autonomy with age. In this study it was apparent  
22  
23 461 from interviews that, even at a young age, issues of the child's autonomy could affect  
24  
25 462 the parent-child relationship and lead to family conflict. Previous studies have shown  
26  
27 463 that families often experience conflicts in chronic disease care setting. In particular,  
28  
29 464 children with T1DM and high levels of family conflict have been shown to have  
30  
31 465 poorer blood glucose control and lower overall quality of life<sup>[31 32]</sup>. As young children  
32  
33 466 grow into adolescence, these conflicts may become more common or escalate.  
34  
35 467 Khandan (2018)<sup>[33]</sup> found that when children with T1DM reached the age of 8 to 11,  
36  
37 468 their parents begin to transfer diabetes management responsibility to them, gradually  
38  
39 469 transitioning from "parental responsibility" to "cooperative support." While parents  
40  
41 470 have a high degree of control over their young child's medical care, they may require  
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43 471 outside support from clinicians or the community in transitioning these  
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45 472 responsibilities as their child enters adolescents. Appropriate mental health and  
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47 473 community support may thus improve outcomes among these children and their  
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49 474 caregivers and help to achieve an effective transition to self-management as these  
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51 475 children enter adolescence.  
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3 476 **Improving Financial and Social Support Systems for Parental Caregivers of**  
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5 477 **Children with T1DM in China**  
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7  
8 478 In this study parental caregivers of children with T1DM consistently reported a strain  
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10 479 on household finances related to their child's care and disposable supplies, and a lack  
11  
12 480 of social support. In the majority of cases, discussed in the present study, expenses  
13  
14 481 were covered by insurance only during hospital stay, but after discharge the expenses  
15  
16 482 were paid by parents/guardians. Insulin medication was also partly covered by health  
17  
18 483 insurance, but the reimbursement rate varied depending on the type of health  
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20 484 insurance (up to 90%). Similar to the results of other studies<sup>[34]</sup>, medications and  
21  
22 485 disposable devices used for long-term treatment place a substantial and ongoing  
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24 486 burden on these families, often affecting housing, employment, and economic  
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26 487 opportunities for middle- and low-income families. Financial burden not only affects  
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28 488 the physical and mental health of parental caregivers, but also limits or delay selection  
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30 489 of treatment options that can influence the T1DM child's long-term prognosis.  
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33  
34 490 Furthermore, the lack of social support and relative social isolation of caregivers,  
35  
36 491 particularly those that reduced hours or left jobs to act as primary caregivers (most  
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38 492 common among mothers), was consistently reported in this study. The lack of support  
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40 493 systems was apparent from limited family social activities, which often negatively  
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42 494 impacted the parental caregiver's emotional state. Compared to other developed  
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44 495 regions, China currently has a lack of diabetes nurses in kindergartens and primary or  
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46 496 secondary schools. Thus, preschool and school-age children have to assume the  
47  
48 497 responsibility of diabetes self-management during school hours. In addition many  
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50 498 parents in this study reported that blood sugar control was not ideal during school  
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52 499 hours, because of self-esteem issues or poor self-control. Therefore, we propose that  
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54 500 we should, as a healthcare system, selectively learn from the successful experience of  
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3 501 other countries<sup>[35]</sup> and gradually implement training for school personnel and other  
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5 502 personnel who contact with diabetic children, to improve the social support system for  
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8 503 children with diabetes.  
9

10 504 Notably, this research is limited by the interpretation of the reviewers and coders. In  
11  
12 505 particular, all interviewees and researchers were from a single hospital, which limits  
13  
14 506 the generalizability of the findings to a broader population. However, these insights  
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16 507 provide greater depth than mere quantitative characterizations, and may aid in  
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18 508 improving both psychological and physical outcomes of children with T1DM and  
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20 509 their parental caregivers.  
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## 25 26 511 **Conclusions**

27  
28 512 This qualitative study employs grounded theory methods to examine the emergent  
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30 513 themes through a series of interviews that address the perceptions of parental  
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32 514 caregivers of children with T1DM, giving voice to the common challenges faced by  
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34 515 parental caregivers as their young children are first diagnosed with T1DM and slowly  
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36 516 gain autonomy for their own chronic disease management with age. This research  
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38 517 demonstrates common themes of persistent psychological stress, difficulty managing  
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40 518 changes in family function, challenges in daily disease management, challenges of  
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42 519 excessive financial burden, and the impact of a lack of social support for parental  
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44 520 caregivers. By characterizing these common perceptions and experiences, we can  
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46 521 better prepare health care providers to support both the T1DM child and parental  
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48 522 caregivers as they adapt to medical management of T1DM at different stages, thereby  
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50 523 improving their self-management capabilities.  
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5 527 **List of abbreviations**  
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7  
8 528 T1DM: Type 1 Diabetes Mellitus  
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10 529 QoL: Quality of life  
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12 530 GT: Grounded Theory  
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14 531 PTSD: posttraumatic stress disorder  
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16 532 IRB: Institutional Review Board  
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4

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6  
7  
8 536 public, commercial or not-for-profit sectors  
9

10 537 **Competing interests:** The authors declare no conflicts of interest in this study.  
11

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13  
14  
15 539 performed by Huijuan Tong. Data were coded and interpreted by Dr. Feng Qiu and  
16  
17 540 Dr. Huijuan Tong. The manuscript was written by Huijuan Tong and Ling Fan.  
18

19 541 **Ethics approval and consent to participate:** This study was conducted in  
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21 542 accordance with the Declaration of Helsinki and was approved by the Institutional  
22  
23  
24 543 Review Board (IRB) of Shengjing Hospital, China Medical University, Shenyang,  
25  
26 544 China (Approval no. 2018PS362K). All participants provided written informed  
27  
28 545 consent prior to participating in interviews.  
29

30 546 **Consent for publication:** Not applicable  
31

32 547 **Availability of data and materials:** The data set supporting the results of this article  
33  
34  
35 548 are included within the article. The datasets used and/or analysed during the current  
36  
37 549 study are available from the corresponding author on reasonable request.  
38

39  
40 550 **Word count:** 5316  
41

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668 **Table 1 Semi-Structured Interview Outline for Parents of Children Aged ≤14**  
 669 **with Type 1 Diabetes Mellitus (T1DM Caregiving Parents)**

| Question # | Description  |
|------------|--|
| 1          | Could you please talk about the situation when your child was first diagnosed with type 1 diabetes and your reaction at that time?               |
| 2          | Could you please describe a day of caring for a child with type 1 diabetes?  |
| 3          | Since your child was diagnosed with diabetes, what has been your biggest concern, or what is the most difficult issue you have had to deal with? |
| 4          | How do you help your child manage his/her diet?  |
| 5          | How do you help your child manage his/her medication?  |
| 6          | How do you help your child manage his/her activities or exercise?  |
| 7          | How do you help your child manage his/her emotions?  |
| 8          | How do you manage your own life while taking care of your child?   |
| 9          | As a caregiver, what are your needs in caring for the child?   |
| 10         | Do you think you are qualified for the role of caring for a child with type 1 diabetes?  |

670 Note: This outline has been translated from the original Mandarin Chinese version.  
 671 All interviews were conducted in the local language of the investigator (Mandaring  
 672 Chinese).

674 **Table 2 Characteristics of Parental Caregivers of T1DM Children (T1DM**  
 675 **Caregiver Parents) Interviewed**

| Characteristic                                  | Interviewee<br>(n = 20) |
|---|-------------------------|
| Children  |                         |
| Age (years), mean±SD                            | 10.6±2.45               |
| Onset age of T1DM, mean±SD                      | 7.2±2.4                 |
| Insulin regimen, n (%)                          |                         |
| Insulin pump use                                | 8 (40%)                 |
| Daily injections                                | 12 (60%)                |
| Gender, n (%)                                   |                         |
| Male  | 7 (35%)                 |
| Female  | 13 (65%)                |
| Parents   |                         |
| Age(year), mean±SD                              | 39.45±6.21              |
| Gender, n (%)                                   |                         |
| Male (self-identify as Father)                  | 8(40%)                  |
| Female (self-identify as Mother)                | 12(60%)                 |
| Current employment status, n (%)                |                         |
| Full-time                                       | 8 (40%)                 |
| Part-time                                       | 6 (30%)                 |
| Not working                                     | 6 (30%)                 |
| Highest education level, n (%)                  |                         |
| Junior high (middle) school or some high school | 6 (30%)                 |
| High school diploma                             | 6 (30%)                 |

|    |   |         |
|----|---|---------|
| 1  |   |         |
| 2  |   |         |
| 3  | Technical school (2-year degree or equivalent)  | 3 (15%) |
| 4  |   |         |
| 5  | Bachelor's degree (4-year degree or equivalent) | 5 (25%) |
| 6  |   |         |
| 7  |   |         |
| 8  | Monthly Income (CNY/USD), n (%)                 |         |
| 9  |   |         |
| 10 | < 3077/500                                      | 5 (25%) |
| 11 |   |         |
| 12 | 3077-11428/500-1700                             | 9 (45%) |
| 13 |   |         |
| 14 |   |         |
| 15 | >11428/1700                                     | 6 (30%) |
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For peer review only



677 **Table 3 Themes and Sub-themes Emerging from Interviews of Parental**  
 678 **Caregivers of T1DM Children (T1DM Caregiver Parents)**

| Themes                          | Subthemes  |
|---------------------------------|--|
| Persistent psychological stress | (1) catastrophic emotional experience<br>(2) emotional distress based in negative emotions<br>(3) altered sense of self-efficacy<br>(4) perceived increased responsibility for parenting                         |
| Family function changes         | (1) changes in patterns of family life<br>(2) changes in parental roles and functions  |
| Challenges in daily management  | (1) technical difficulties managing blood glucose<br>(2) difficulties in emotional regulation and managing parent-child conflict<br>(3) transition from parental management to self-management as the child ages |
| Excessive financial burden      | (1) burden of disease treatment<br>(2) changes in economic sources   |
| Lack of social support system   | (1) limited social activities<br>(2) insufficient other support systems  |

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Table Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

| No   | Item                                     | Guide questions/description  | Page  |
|--|--|--|-------|
| <b>Domain 1:<br/>Research team<br/>and reflexivity</b> |  |  |       |
| Personal<br>Characteristics                            |  |  |       |
| 1.   | Interviewer/facilitator                  | Which author/s conducted the interview or focus group?   | 24    |
| 2.   | Credentials                              | What were the researcher's credentials? <i>E.g. PhD, MD</i>  | 01,24 |
| 3.   | Occupation                               | What was their occupation at the time of the study?  | 24    |
| 4.   | Gender                                   | Was the researcher male or female?   | 24    |
| 5.   | Experience and training                  | What experience or training did the researcher have?   | 08    |
| Relationship with participants                         |  |  |       |
| 6.   | Relationship established                 | Was a relationship established prior to study commencement?  | 07    |
| 7.   | Participant knowledge of the interviewer | What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>                                  | 08    |
| 8.   | Interviewer characteristics              | What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i> | 08    |
| <b>Domain 2: study design</b>                          |  |  |       |

| No                    | Item                                  | Guide questions/description   | Page        |
|-----------------------|---------------------------------------|---|-------------|
| Theoretical framework |                                       |   |             |
| 9.                    | Methodological orientation and Theory | What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i> | 09          |
| Participant selection |                                       |   |             |
| 10.                   | Sampling                              | How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>   | 07          |
| 11.                   | Method of approach                    | How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>  | 08          |
| 12.                   | Sample size                           | How many participants were in the study?  | 09          |
| 13.                   | Non-participation                     | How many people refused to participate or dropped out? Reasons?   | 07          |
| Setting               |                                       |   |             |
| 14.                   | Setting of data collection            | Where was the data collected? <i>e.g. home, clinic, workplace</i>   | 08          |
| 15.                   | Presence of non-participants          | Was anyone else present besides the participants and researchers?   | 08          |
| 16.                   | Description of sample                 | What are the important characteristics of the sample? <i>e.g. demographic data, date</i>  | 10, Table 2 |
| Data collection       |                                       |   |             |
| 17.                   | Interview guide                       | Were questions, prompts, guides   | 08          |

| No   | Item                           | Guide questions/description  | Page |
|--|--------------------------------|--|------|
|  |                                | provided by the authors? Was it pilot tested?                            |      |
| 18.  | Repeat interviews              | Were repeat interviews carried out? If yes, how many?                    | n/a  |
| 19.  | Audio/visual recording         | Did the research use audio or visual recording to collect the data?      | 09   |
| 20.  | Field notes                    | Were field notes made during and/or after the interview or focus group?  | 09   |
| 21.  | Duration                       | What was the duration of the interviews or focus group?                  | 08   |
| 22.  | Data saturation                | Was data saturation discussed?   | 07   |
| 23.  | Transcripts returned           | Were transcripts returned to participants for comment and/or correction? | 09   |
| <b>Domain 3:<br/>analysis and findings</b> |                                |  |      |
| Data analysis                              |                                |  |      |
| 24.  | Number of data coders          | How many data coders coded the data?                                     | 09   |
| 25.  | Description of the coding tree | Did authors provide a description of the coding tree?                    | 09   |
| 26.  | Derivation of themes           | Were themes identified in advance or derived from the data?              | 09   |
| 27.  | Software                       | What software, if applicable, was used to manage the data?               | 09   |
| 28.  | Participant checking           | Did participants provide feedback on the findings?                       | 09   |

| No        | Item                         | Guide questions/description  | Page           |
|-----------|------------------------------|--|----------------|
| Reporting |                              |  |                |
| 29.       | Quotations presented         | Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i> | 10-16          |
| 30.       | Data and findings consistent | Was there consistency between the data presented and the findings?   | 17             |
| 31.       | Clarity of major themes      | Were major themes clearly presented in the findings?   | 10,17, Table 3 |
| 32.       | Clarity of minor themes      | Is there a description of diverse cases or discussion of minor them  | 10, Table 3    |