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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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2
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))
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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.**

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

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32
33 **14 Results:** Content analysis revealed 5 common themes with 14 subthemes, including
34
35 **15 persistent psychological stress (catastrophic emotions, emotional distress, and altered**
36
37 **16 self-efficacy), family function change (altered family life patterns and changes in**
38
39 **17 parental role/function), challenges in daily management (technical challenges,**
40
41 **18 emotional regulation, parent-child conflict, and transition of care autonomy from parent**
42
43 **19 to child), financial burden (cost burden of treatment and altered family economics), and**
44
45 **20 lack of social support (social activity limitations and insufficient support systems). All**
46
47 **21 were highly saturated across interview data.**

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51 **22 Conclusions:** Young children with T1DM rely on parental caregivers for disease
52
53 **23 management and to one day become capable of autonomous self-management as they**
54
55 **24 age. However, both the period of emotional disturbance during initial diagnosis,**
56
57 **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
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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.

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

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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
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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
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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.
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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 unit¹. 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 worldwide².
54 In China, the incidence of T1DM in children is currently 5.6 per 100,000 live births³.
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 year⁴. 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^{5,6}. 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 management⁷. 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 grows⁸. These responsibilities place immense psychological financial stress on

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3 73 parental caregivers.
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5 74 Owing to the relatively lower incidence of T1DM outside of urban centers in China,
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7
8 75 the emotional toll, financial burden, and social isolation experienced by parental
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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 control⁹. 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%)¹⁰. This can lead to complications
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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.
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31 85 Rankin et al. (2018)¹ used qualitative methods to examine the strategies and motivations
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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 management¹¹. 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 diagnosed¹². These feelings may be transient or persist, and may
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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 anxiety¹³⁻¹⁵. 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 children¹⁵, psychological state¹⁶ and coping style of the children or their
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14 103 parents¹⁷.

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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
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21 106 T1DM¹. This socio-ethnographic study employs qualitative methods to examine the
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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
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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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37 **Methods**

38 **Study Population and Design**

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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
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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
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52 120 attending visits with children hospitalized or assessed in the Pediatric
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54 121 Neuroendocrinology Department of Shengjing Hospital, China Medical University in
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3 123 Shenyang from January 2018 to June 2019.
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5 124 To be eligible for participation in study interview, T1DM Caregiving Parents were
6
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 period¹⁸ 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;
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17 130 (2) the child with T1DM was considered to required immediate medical care or
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19 131 treatment where the study could pose an undue burden on the patient or caregiver; (3)
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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
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32 136 Medical University, Shenyang, China (Approval no. 2018PS362K). All participants
33
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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39 139 Purposive nonprobability sampling was used, in which eligible T1DM Caregiving
40
41 140 Parents were approached for participation as they presented in clinic. To ensure a
42
43 141 representative sample, the heterogeneity of sample selection was expanded for T1DM
44
45 142 Caregiving Parent age, marital status, education level, and T1DM child age and disease
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47 143 course. The study was discontinued when qualitative data reached saturation, which
48
49 144 was expected to occur between 15 and 20 interviews, as previously described^{19,20} When
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51 145 the number of interviews reached 20, the data in our research was saturated, and no new
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53 146 information was obtained, so sampling was terminated.
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57 147 **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
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7 150 individual and family self-management²¹, 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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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,
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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
26
27 159 starting each interview.

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31 160 The interview location was selected as audio visual classroom located in the Pediatric
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33 161 Neuroendocrinology Ward. This location was selected for the quiet environment, free
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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**

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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
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53 170 and allowed to suggest corrections, which, where appropriate, were assessed and
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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 methods²⁰ 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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17 179 Textual coding results in NVivo 11.0 (QSR International) were reported as counts and
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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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35 189 Saturation was reached when 20 T1DM Caregiving Parents (N = 20) completed
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37 190 interviews. Interviewed T1DM Caregiving Parents were aged 30 to 53 years of age
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39 191 (10.6±2.45), including 7 fathers and 13 mothers (gender roles were self-identified by
40
41 192 the interviewee). Of these patients, 8 were caregivers of children with T1DM that were
42
43 193 treated with islet pumps, and 12 were caregivers of children with T1DM that were
44
45 194 treated with subcutaneous injections. Socio-demographic information for T1DM
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47 195 Caregiving Parents completing interviews and demographic and clinical condition of
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49 196 their children are summarized in **Table 2**.

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51 197 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
8 200 burden; (5) lack of support system. Further, 14 subthemes within these 5 themes,
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10 201 summarized in **Table 3**. The themes/sub-themes are further characterized below.

12 202 **Theme of Persistent Psychological Stress**

14
15 203 Persistent psychological stress was identified as prominent theme across interviews,
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17 204 with four key sub-themes emerging from coding:

19 205 **(1) Catastrophic Emotional Experience**

21 206 In acute period following diagnosis, parents often experienced emotions that can be
22
23 207 described as catastrophic, including shock, fearfulness, frustration, hopelessness,
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25
26 208 sadness, and feelings that disaster is imminent.

28 209 Interviewee DM2: "When the doctor told me that my child was diabetic, I felt like [I
29
30 210 was] struck by lightning and the sky was falling. My child's life is basically over."

33 211 **(2) Emotional Distress Based in Negative Emotions**

35 212 Negative emotions observed in T1DM Caregiver Parents primarily included continual
36
37 213 worry, anxiety, sadness, stigma, annoyance, and guilt. Worry was embodied in anxiety
38
39 214 and sadness, often with connections to the uncertainty of disease progression in their
40
41 215 child. Some parents also experienced symptoms of worry and invasive thoughts about
42
43 216 the potential for their children to be discriminated against in the future because of their
44
45 217 illness, leading some to even report hiding their child's illness in common social
46
47 218 contexts. Further, parents reported feeling guilt linked to social isolation and dietary
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49 219 restrictions experienced by their child, etiology of illness (often linked to limited
50
51 220 clinical understanding of T1DM), or feeling of being "at fault" for their child's
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54 221 condition.

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58 222 Interviewee DM2: "It's still like a sword hanging over my head. I don't know when the
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3 223 complications will come. I live with fear every day."
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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
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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.
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32 238 Interviewee DM6: "Taking care of [my daughter], it's not that I think I can or can't, but
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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. "

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8 250 **Altered Facility Function**

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10 251 Changes in family life included two prominent subthemes:

11
12 252 **(1) Changes in Patterns of Family Life**

13
14 253 Changes in routine patterns of daily living within the family unit were consistently
15
16 254 reported by T1DM Caregiver Parents. These changes included changes in family
17
18 255 activities designed to assist children in adapting to their life after T1DM diagnosis. On
19
20 256 one hand, parents reported striving to retain normalcy for their children; however, the
21
22 257 child's T1DM was also often reported to be disruptive to others, particularly other
23
24 258 children, in the family unit. Parents also reported aiming to incorporate blood glucose
25
26 259 measurement in routine daily living activities of the family unit, with mixed success.

27
28 260 Interviewee DM16: "It is inevitable that [when living with a child with T1DM] you
29
30 261 can't be the same as other families. We have to consider our child's physical strength
31
32 262 and whether [he] can eat regularly. Especially when faced with a table of good food, it
33
34 263 is uncomfortable for the child to see others eating.

35
36 264 Interviewee DM18: "Now we guide our child to think that measuring blood glucose
37
38 265 and injecting insulin is a routine in life, just like showers before bed. We don't want
39
40 266 our child to feel that injecting insulin before meals is a burden."

41
42 267 **(2) Changes in Parental Role and Function**

43
44 268 T1DM Caregiver Parents consistently reported that they perceived differences between
45
46 269 their "normal" role and function compared with their prior lifestyle before their child's
47
48 270 diagnosis. Specifically, T1DM Caregiver Parents expressed that their child's diagnosis
49
50 271 affected their future career planning, life focus, and goals, and often resulting in a
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52 272 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
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5 274 off work as soon as possible. I used to leave early and return late to make money. Now
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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.

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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**

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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.

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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
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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
7 350 T1DM, T1DM Caregiver Parents reported feeling disruption in the social activities of
8
9 351 the family unit. In particular, mothers in the interview often left their employment,
10
11 352 changed careers, or reduced hours to allow for caregiving for their child with T1DM.
12
13 353 This transition can result in social isolation and limit normal social activities of the
14
15 354 parent.

16
17 355 Interviewee DM10: "Since my child had a ketosis coma, I have never dared to relax
18
19 356 again. I have lost myself. Every day in the year, there are no more visits to relatives or
20
21 357 friends."
22
23

24 358 **(2) Insufficient Other Support Systems**

25
26 359 Insufficient other systems of social support was a common concern of T1DM Caregiver
27
28 360 Parents, especially those of children reaching school age and assuming autonomy over
29
30 361 their care during school hours.
31
32

33
34 362 Interviewee DM12: "Unlike other countries, our children do not have diabetes nurses
35
36 363 in school. When the child is at school, every time the teacher calls, I am terrified, always
37
38 364 scared that something bad will happen. If the child's blood glucose is low, does the
39
40 365 teacher know how to handle it? Will it be delayed?"
41
42

43 366 **Discussion**

44
45 367 This study employed qualitative research methods via semi-structured interviews with
46
47 368 parental caregivers of children with T1DM. Using Grounded Theory (GT), a method
48
49 369 based in social science research, ^[20-21] the researchers examined and consolidated
50
51 370 emergent themes from interview transcripts. GT methods are designed to allow
52
53 371 emergence of previously undetected patterns or trends in social communications. In this
54
55 372 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^{20,22-24}; 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
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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 research²⁵.

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 for²⁶. 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 T1DM²⁷.
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
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41 417 discrimination. Stigma affects caregivers by playing on their guilt, which may be
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43 418 exacerbated by "causing" the child pain through blood tests and limiting activities or
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45 419 diet. Some parents also have limited scientific understanding of the illness, and perceive
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47 420 the disease to be a result of negligent in care that can further exacerbate feeling of guilt,
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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 children²⁸. Thus, the emotional state of the parental caregiver is of
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5 424 concern to medical staff treating children with T1DM.
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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 control²⁹. 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
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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
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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
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45 442 children with T1DM, parental caregivers will need to dedicate substantial time and
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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
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51 445 handling emergent issues. Common challenges in daily management include difficulty
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53 446 in blood glucose management, emotional management, parent-child conflict, and the
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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
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5 449 monitoring, often young children may not have access to these technologies or
6
7 450 compliance may not be possible³⁰. 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.
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15 454 Parental caregivers of children with T1DM also face challenges in transitioning their
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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
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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^{31,32}. As young children grow into
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29 461 adolescents, these conflicts may become more common or escalate. Khandan (2018)³³
30
31 462 found that when children with T1DM reached the age of 8 to 11, their parents begin to
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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
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41 467 adolescents. Appropriate mental health and community support may thus improve
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43 468 outcomes among these children and their caregivers and help to achieve an effective
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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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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 studies³⁴, 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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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
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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,
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39 490 as a healthcare system, selectively learn from the successful experience of other
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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
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45 493 children with diabetes.

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49 494 Notably, this research is limited by the interpretation of the reviewers and coders. In
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51 495 particular, all interviewees and researchers were from a single hospital, which limits
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53 496 the generalizability of the findings of this study to a broader population. However, these
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55 497 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
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5 499 with T1DM and their parental caregivers.
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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-
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34 513 management capabilities.
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40 514 **List of abbreviations**

41
42 515 T1DM: Type 1 Diabetes Mellitus
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44 516 QoL: Quality of life
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46 517 GT: Grounded Theory
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48 518 PTSD: posttraumatic stress disorder
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50 519 IRB: Institutional Review Board
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3 521 **Declarations**
4

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6

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8

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11 Huijuan Tong. The manuscript was written by Huijuan Tong and Ling Fan.
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16

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18 with the Declaration of Helsinki and was approved by the Institutional Review Board
19 (IRB) of Shengjing Hospital, China Medical University, Shenyang, China (Approval
20 no. 2018PS362K). All participants provided written informed consent prior to
21 participating in interviews.
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29 532 **Consent for publication:** Not applicable

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

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For peer review only

645 **Table 1 Semi-Structured Interview Outline for Parents of Children Aged ≤ 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 (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%)

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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 (%)	
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9		
10	< 3077	5 (25%)
11		
12	3077 to -11428	9 (45%)
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14	>11428	6 (30%)
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For peer review only

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

Themes		Subthemes
Persistent stress	psychological	(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	in daily	(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	social support	(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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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 ± 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

1
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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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16

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.
33
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
5 influenced by its burden. Although the incidence of T1DM in China is lower than that
6
7 in Europe or the United States, being currently 5.6 per 100,000 live births[3], China
8
9 ranks fourth among countries for T1DM occurrence — and the number of cases is
10
11 increasing each year[4]. However, rural communities in China generally have fewer
12
13 resources and growing number of T1DM cases outside of urban centers would
14
15 eventually increase the strain on Chinese parental caregivers. Thus, examining the
16
17 situation of middle- and low-income parents of children with T1DM in China is
18
19 essential to improving resources for T1DM care and long-term outcomes.
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23
24 Management of T1DM in children involves changes in daily living activities that affect
25
26 not only the child receiving care but also the caregiver, including responsibility to
27
28 ensure continuous glucose monitoring (4 or more times per day) and insulin injection
29
30 using an insulin pump or injecting insulin multiple times a day, as well as tracking and
31
32 calculating daily carbohydrate intake and physical activity levels important to
33
34 prevention of hypoglycemic and hyperglycemic episodes[5, 6]. Majority of children
35
36 with T1DM under age of 13 are unable to self-manage their T1DM care, and instead
37
38 rely heavily on their parental caregiver for disease management[7]. Treatment for
39
40 children with T1DM is aimed at ensuring stable blood glucose levels, minimizing
41
42 occurrence of potentially severe hypoglycemic events, and preventing long-term
43
44 complications of diabetes as the child grows[8]. These responsibilities presumably
45
46 place immense psychological and financial stress on parental caregivers.
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50
51 Owing to the relatively lower incidence of T1DM outside of urban centers in China,
52
53 the emotional toll, financial burden, and social isolation experienced by parental
54
55 caregivers of young children with T1DM can be immense. Despite improvements in
56
57 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
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9 can lead to complications, that have adverse impact on the child's growth and long-
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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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19 Rankin et al. (2018)[1] used qualitative methods to examine the strategies and
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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
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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.
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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
42
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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To be eligible for participation in study interview, T1DM Caregiving Parents were required to (1) be the parent and/or legal guardian of a child 14 years of age or younger with diagnosed T1DM, and (2) be a primary caregiver during at least 6 months of continuous care for child being treated for T1DM during this period[18] T1DM Caregiving Parents were considered ineligible to participate in interviews if (1) the child with T1DM also experienced other significant comorbidities or chronic diseases; (2) the child with T1DM was considered to require immediate medical care or treatment and the study could pose an undue burden on the patient or caregiver; (3) T1DM Caregiving Parent was unable to communicate fluently in the local language of the investigator (Mandarin Chinese).

This study was conducted in accordance with the Declaration of Helsinki and was approved by the Institutional Review Board (IRB) of Shengjing Hospital, China Medical University, Shenyang, China (Approval no. 2018PS362K). All participants provided written informed consent prior to participating in interviews.

Sampling Methods and Process

Purposive nonprobability sampling was used, in which eligible T1DM Caregiving Parents were approached for participation as they visited clinic. To ensure a representative sample, the heterogeneity of sample selection was expanded for T1DM Caregiving Parent age, marital status, education level, and T1DM child age and disease course. The study was discontinued when qualitative data reached saturation, which was expected to occur between 15 and 20 interviews, as previously described[19, 20] When the number of interviews reached 20, the data in our research was saturated, and no new information was obtained, so sampling was terminated.

Data Collection

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

1
2
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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15 Upon arrival at the clinical site, the head nurse of the clinical unit familiar with the
16 T1DM Caregiving Parent met the interviewee, led them to the interview site, and made
17 introductions. Prior to the start of the interview, the interviewer explained the purpose,
18 significance, methods, rights of the interviewee, and privacy protection measures.
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Written informed consent was then obtained before starting each interview.

The interview location was selected as audio visual classroom located in the Pediatric Neuroendocrinology Ward. This location was selected for the quiet environment, free of distractions. Interviews were conducted by the authors, who were provided with training on semi-structured interviews and use of neutral, objective, and non-leading language during the interview to maximize data integrity.

Data Transcription and Coding

Each interview was recorded using audio recording devices, and digitally transcribed asynchronously (with 48 hours after each interview) by the researchers. Transcripts were recorded in MS Word (Microsoft, USA), and verified by a second researcher. To ensure data integrity, interviewees were provided with a copy of their interview transcript and allowed to suggest corrections, which, if appropriate, were assessed and integrated by the researchers upon review of the original recording.

Heuristic coding was performed using emergent grounded theory methods[20] manually using transcripts imported into NVivo 11.0 (QSR International, USA) using manual code to summarize text data, and identify and refine themes. Coding was

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2
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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30 **Results**

31 **Participant Characteristics**

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

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10 Persistent psychological stress was identified as prominent theme across interviews,
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12 with four key sub-themes emerging from coding:
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15 **(1) Catastrophic Emotional Experience**

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17 In acute period following diagnosis, parents often experienced emotions that can be
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19 described as catastrophic, including shock, fearfulness, frustration, hopelessness,
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21 sadness, and feelings that disaster is imminent.
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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."
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29 **(2) Emotional Distress Based in Negative Emotions**

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31 Negative emotions observed in T1DM Caregiver Parents primarily included continual
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33 worry, anxiety, sadness, stigma, annoyance, and guilt. Worry was embodied in anxiety
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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,
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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
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45 experienced by their child, etiology of illness (often linked to limited clinical
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47 understanding of T1DM), or feeling of being "at fault" for their child's condition.
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51 Interviewee DM2: "It's still like a sword hanging over my head. I don't know when the
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53 complications will come. I live with fear every day."
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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**

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21 T1DM Caregiver Parents also showed self-doubt owing to lack of experience in chronic
22 disease care. In the most extreme cases, these feelings manifest as a severe lack of self-
23 compassion, wherein parents expressed doubt in their ability to competently care for
24 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**

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40 T1DM Caregiver Parents reported perceiving a heavier burden of responsibility to
41 manage their child's disease and remain hypervigilant, in particular for young children
42 with T1DM not capable of self-managing. Parents perceive that, compared to children
43 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:
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5 **(1) Changes in Patterns of Family Life**
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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
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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
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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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5 In some cases significant housing and job/school changes are made to accommodate
6 the child’s T1DM care.
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8 Interviewee DM14: "My family is in the countryside, but our child comes to a school
9 in the city. Since our child has the disease, diabetes, and cannot live in school, I have
10 to accompany him to study. My child and I rented a house near the school, which is
11 convenient for me to take care of him, and we will return to the countryside during
12 vacation, where his father works.
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21 **Challenges in Daily Management Theme**

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

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

55 In addition to the regulation of T1DM Caregiver Parents’ own emotions, interviewees
56 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**

48 With changes in their child's growth and developmental stage, the roles and function
49 of children and parents in T1DM management shifts. However, premature transfer of
50 diabetes management tasks to children with T1DM is now considered a factor leading
51 to poor blood glucose control. Many T1DM Caregiver Parents expressed uncertainty or
52 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.
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10 Interviewee DM10: "Since my child had a ketosis coma, I have never dared to relax
11 again. I have lost myself. Every day in the year, there are no more visits to relatives or
12 friends."
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15 **(2) Insufficient Other Support Systems**

16 Insufficient systems of social support were a common concern of T1DM Caregiver
17 Parents, especially those of children reaching school age and assuming autonomy over
18 their care during school hours.
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21 Interviewee DM12: "Unlike other countries, our children do not have diabetes nurses
22 in school. When the child is at school, every time the teacher calls, I am terrified, always
23 scared that something bad will happen. If the child's blood glucose is low, does the
24 teacher know how to handle it? Will it be delayed?"
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31 **Discussion**

32 This study aimed to qualitatively examine perception of common challenges among
33 parental caregivers of children with T1DM. Using Grounded Theory (GT), a method
34 based in social science research, [20-21] the researchers examined and consolidated
35 emergent themes from interview transcripts. In this study, parental caregivers of T1DM
36 children consistently reported persistent psychological stress, changes in routine
37 functions of the family unit, challenges in daily disease management for both the child
38 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.
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7 **Reducing Persistent Psychological Strain in Parental Caregivers of Children with** 8 **T1DM Experience** 9

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11 This study showed that parental caregivers of children with T1DM were particularly
12 susceptible to psychological stress during the early stages after their child's first T1DM
13 diagnosis. These stressors manifested as recollections of negative emotions leading to
14 emotional distress, including shock, sadness, and anxiety. Further, repeat insulin
15 injections and finger blood glucose monitoring in child posed not only technical
16 challenges for non-medical professional caregivers, but also emotional distress in
17 parental caregivers. Shortly after a child's diagnosis, many parental caregivers reported
18 feelings of disbelief, resulting in catastrophic emotional disturbances linked to shock,
19 fear, frustration, despair, and sadness. These findings are consistent with other
20 quantitative psychological studies demonstrating posttraumatic stress disorder (PTSD)
21 symptoms in caregivers[20, 22-24]; however, the use of qualitative interview methods
22 enables additional insights into the character of reflective perceptions of parental
23 caregivers, and how such condition can be relieved. Our study suggests that the
24 emotional effects of "invisibility" of the T1DM prior to diagnosis can trigger guilt and
25 anxiety that exacerbate psychological stressors. Further, young age of the child and
26 uncertainty of social impact can also exacerbate the psychological effects on the
27 caregiver, leading to heightened anxiety and PTSD manifestations. In some cases, these
28 stressors can lead to catastrophic emotional experiences occurred in the early stage of
29 diagnosis and during a child's hospitalization, which is consistent with other
30 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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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.
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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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17 Through a series of interviews that examined the perceptions of parental caregivers of
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19 children with T1DM, this qualitative study employs grounded theory methods to
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21 examine the emergent themes in these conversations, often anecdotally experiences by
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23 health care professionals. This research gives voice to the common challenges faces by
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25 parental caregivers as their young children are first diagnosed with T1DM and slowly
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27 gain autonomy for their own chronic disease management with age. This research
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29 demonstrated common themes of persistent psychological stress, difficulty managing
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31 changes in family function, challenges in daily disease management, challenges of
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33 excessive financial burden, and the impact of a lack of social support for parental
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35 caregivers. By characterizing these common perceptions and experiences, we can better
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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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58 GT: Grounded Theory
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3 PTSD: posttraumatic stress disorder
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5 IRB: Institutional Review Board
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7 **Declarations**

8
9
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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.
30

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32

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Table 1 Semi-Structured Interview Outline for Parents of Children Aged ≤ 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 (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/USD), n (%)	
8		
9		
10	< 3077/500	5 (25%)
11		
12	3077-11428/500-1700	9 (45%)
13		
14	>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)

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 emotional regulation and managing parent-child conflict (3) 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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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:** 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
9
10
11 **4 common challenges among parental caregivers of children with T1DM.**

12
13 **5 Setting:** 45-60 minutes long semi-structured interviews were conducted with T1DM
14
15 **6 Parental Caregivers.** Interview recordings were transcribed and coded in NVivo 11.0
16
17 **7 to observe emergent themes.**

18
19 **8 Participants:** Eligible T1DM Caregiving Parents (parent(s) and/or legal guardian(s))
20
21 **9 were identified from caregivers attending visits with children hospitalized or assessed**
22
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.**

27
28 **12 Primary and secondary outcome measures:** Not applicable.

29
30
31 **13 Results:** A total of 20 T1DM Caregiving Parents were interviewed, aged 30 to 53
32
33 **14 years, including 7 fathers and 13 mothers, with their children mean age of 10.6 ± 2.45**
34
35 **15 years.** Content analysis revealed 5 major themes with 13 subthemes, including
36
37 **16 persistent psychological stress (catastrophic emotions, emotional distress, and altered**
38
39 **17 self-efficacy), family function change (altered family life patterns and changes in**
40
41 **18 parental role/function), challenges in daily management (technical challenges,**
42
43 **19 emotional regulation, parent-child conflict, and transition of care autonomy from**
44
45 **20 parent to child), financial burden (cost burden of treatment and altered family**
46
47 **21 economics), and lack of social support (social activity limitations and insufficient**
48
49 **22 support system).**

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54 **23 Conclusions:** Period of emotional disturbance during initial diagnosis, psychological
55
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

1
2
3 51 impact on the family unit^[1]. With the incidence of T1DM increasing by 2% to 5%
4
5 52 each year worldwide^[2], 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
8
9 54 in Europe or the United States, being currently 5.6 per 100,000 live births^[3], China
10
11 55 ranks fourth in the world for T1DM occurrence — and the number of cases is
12
13 56 increasing each year^[4]. In addition, rural communities in China generally have fewer
14
15 57 resources and growing number of T1DM cases outside of urban centers would
16
17 58 eventually increase the strain on Chinese parental caregivers. Thus, examining the
18
19 59 situation of middle- and low-income parents of children with T1DM in China is
20
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
27
28 62 affect not only the child receiving care but also the caregiver. That includes
29
30 63 continuous glucose monitoring (4 or more times per day), ensuring insulin injections
31
32 64 via insulin pump or injecting insulin multiple times a day, tracking and calculating
33
34 65 daily carbohydrate intake as well as physical activity levels important to prevention of
35
36 66 hypoglycemic and hyperglycemic episodes^[5-6]. Majority of children with T1DM
37
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^[7]. Treatment for children with
41
42 69 T1DM is aimed at ensuring stable blood glucose levels, minimizing occurrence of
43
44 70 potentially severe hypoglycemic events, and preventing long-term complications of
45
46 71 diabetes as the child grows^[8]. These responsibilities presumably place immense
47
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,
54
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
4
5 77 adverse health effects due to invasive procedures or ineffective blood glucose
6
7 78 control^[9]; more than 58.6% of children with T1DM in China do not achieve sustained
8
9 79 hemoglobin control (glycosylated hemoglobin lower than 7.5%)^[10], which leads to
10
11 80 complications, that have adverse impact on the child's growth and long-term health,
12
13 81 and place significant burden on caregivers and the family unit. This justifies a
14
15 82 necessity to study T1DM care and its impact on parental caregivers through a social
16
17 83 lens.

18
19
20
21 84 Previously Rankin et al. (2018)^[11] 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^[11]. 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^[12]. 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^[13-15]. 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
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53 100 outcomes for T1DM children. However, current research on the topic in China is
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3 101 primarily limited to quantitative studies on the quality of life (QoL)^[15], psychological
4
5 102 state^[16] and coping style of the children or their parents^[17].
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 T1DM¹. 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
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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.
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31 **Methods**

32 **Patient and Public Involvement**

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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
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56 125 Neuroendocrinology Department of Shengjing Hospital, China Medical University in
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3 126 Shenyang from January 2018 to June 2019.

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5 127 To be eligible for participation in study interview, T1DM Caregiving Parents were
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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^[18]
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^[19]
50
51 148 ^{20]} 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^[21], 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.

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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
55 174 Heuristic coding was performed using emergent grounded theory methods^[20]
56
57 175 manually using transcripts imported into NVivo 11.0 (QSR International, USA) using
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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**

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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 ± 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**.

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58 200 By analyzing the transcripts of interviews, five major emergent themes were observed
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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.

11 12 205 **Theme of Persistent Psychological Stress**

13
14
15 206 Persistent psychological stress was identified as prominent theme across interviews,
16
17 207 with four key sub-themes emerging from coding:

18 19 208 **(1) Catastrophic Emotional Experience**

20
21 209 In acute period following diagnosis, parents often experienced emotions that can be
22
23 210 described as catastrophic, including shock, fearfulness, frustration, hopelessness,
24
25 211 sadness, and feelings that disaster is imminent.

26
27
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."

31 32 214 **(2) Emotional Distress Based in Negative Emotions**

33
34
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
39 217 anxiety and sadness, often with connections to the uncertainty of disease progression
40
41 218 in their child. Some parents also experienced symptoms of worry and invasive
42
43 219 thoughts about the potential for their children to be discriminated in the future
44
45 220 because of their illness, leading some to even report hiding their child's illness in
46
47 221 common social contexts. Further, parents reported feeling guilt linked to social
48
49 222 isolation and dietary restrictions experienced by their child, etiology of illness (often
50
51 223 linked to limited clinical understanding of T1DM), or feeling of being "at fault" for
52
53 224 their child's condition.

54
55
56 225 Interviewee DM2: "It's still like a sword hanging over my head. I don't know when
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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,
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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. "

253 **Altered Facility Function**

254 Changes in family life included two prominent subthemes:

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

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

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

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

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

271 T1DM Caregiver Parents consistently reported that they perceived differences
272 between their "normal" role and function compared with their prior lifestyle before
273 their child's diagnosis. Specifically, T1DM Caregiver Parents expressed that their
274 child's diagnosis affected their future career planning, life focus, and goals, and often
275 resulting in a greater amount of time spent tending medical needs of their child.

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
32 289 Parents, including:

33 290 **(1) Technical Difficulties in Blood Glucose Management**

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36
37 291 T1DM Caregiver Parents reported technical difficulties in blood glucose management,
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39 292 including unsatisfactory or irregular blood glucose levels, primarily associated with
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41 293 dietary control, exercise compliance, untimely blood glucose monitoring, and insulin
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43 294 injection dosage adjustment. Parents expressed that lack of self-management, often
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45 295 owing to social and educational obligations, was often a key concern.

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48 296 Interviewee DM3: "He is in the second grade of junior high school. There is a lot of
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50 297 tutoring outside school. He has to get up at 5:30 in the morning to study and finish
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52 298 school at 5:30 in the evening. If goes to the tutoring class, he returns at 8:30. There is
53
54 299 no time to exercise. At school, his blood glucose control was poor [but] it is
55
56 300 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

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

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

21 334 **Excessive Financial Burden Theme**

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23
24 335 T1DM Caregiver Parents consistently reported the excessive financial burden of
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26 336 caring for a child with T1DM, including high cost of treatment. This burden was often
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28
29 337 cited as a factor for job and educational changes, affecting family member
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31 338 circumstances. Due to the long-term nature of treatment, medications and injection
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33 339 supplies are consumable items with sustained cost impact. Furthermore, caring for a
34
35 340 young child with T1DM often requires care around the clock, with some parents
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38 341 reporting that one of the parents gave up employment, changed employment, or
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40 342 reduced hours to provide adequate care for their child, often decreasing household
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42 343 income and adding further financial stress to middle- and low-income families.

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45 344 Interviewee DM2: "Using an insulin pump is a great economic pressure. It costs
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47 345 nearly 20,000 CNY [about 3000 USD] a year. One tube is normally more than 110
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49 346 CNY [about 17 USD]. I will buy some during sales and let my friends buy some more
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51 347 from other channels. A tube can be used for three days. It costs nearly 20,000 CNY
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53 348 [about 3000 USD] a year."

54 349 **Lack of Social Support Systems Theme**

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58 350 The lack of support system primarily includes limited social activities and insufficient
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3 351 social support system, as described below:
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5 352 **(1) Limited Social Activities**
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8 353 At present, the family structure in China is dominated by a typical nuclear family, and
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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
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14 356 activities of the family unit. In particular, mothers in the interview often left their
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16 357 employment, changed careers, or reduced hours to be able to care for their child with
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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.
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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
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28 362 friends."
29

30 363 **(2) Insufficient Other Support Systems**
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32
33 364 Insufficient systems of social support were a common concern of T1DM Caregiver
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35 365 Parents, especially those of children reaching school age and assuming autonomy over
36
37 366 their care during school hours.
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40 367 Interviewee DM12: "Unlike other countries, our children do not have diabetes nurses
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42 368 in school. When the child is at school, every time the teacher calls, I am terrified,
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44 369 always scared that something bad will happen. If the child's blood glucose is low,
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46 370 does the teacher know how to handle it? Will it be delayed?"
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51 372 **Discussion**
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54 373 This study aimed to qualitatively examine perception of common challenges among
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56 374 parental caregivers of children with T1DM. Using Grounded Theory (GT), a method
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58 375 based in social science research ^[20-21], researchers examined and consolidated
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3 376 emergent themes from interview transcripts. In this study, parental caregivers of
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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.
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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.
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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
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41 394 stress disorder (PTSD) symptoms in caregivers^[20 22-24]; 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
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53 400 pressure on the caregiver, leading to anxiety and PTSD manifestations. In some cases,
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3 401 these stressors can lead to catastrophic emotional experiences occurred in the early
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5 402 stage of diagnosis and during a child's hospitalization, which is consistent with other
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8 403 research^[25].

9
10 404 In particular, following the hospital discharge of a child with T1DM, parental
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12 405 caregivers in this study noted a variety of negative emotions, in particular poorly
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14 406 controlled worry, anxiety, sadness, stigma, annoyance, and guilt. During the course of
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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
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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
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26 411 exert adverse effects on the health and psychological condition of the parental
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28 412 caregivers and the children they care for^[26]. Thus, medical staff should pay particular
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30 413 attention to these potential effects in early stages of the disease progression.

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33 414 Parental caregivers, in part due to their emotional bond with their child, are also
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35 415 affected emotionally by perceived stigma. Stigma refers to a kind of inner shame
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37 416 caused by illness that is viewed as a deficiency, which negatively affects patient
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39 417 psychology and can contribute to noncompliance or delay of critical treatment and
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42 418 monitoring in T1DM^[27]. During the interviews conducted in this study, some parents
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44 419 of children with T1DM expressed that diabetes would affect their child's future
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46 420 employment, marriage, and social standing, in some cases going so far as to hide their
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48 421 child's condition to avoid perceived discrimination. Stigma affects caregivers by
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50 422 playing on their guilt, which may be exacerbated by "causing" pain to the child
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52 423 through blood tests and limiting activities or diet. Some parents also have limited
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54 424 scientific understanding of the illness, and perceive the disease to be a result of
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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,
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5 427 thereby affecting management of blood glucose control in their children^[28]. Thus,
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7 428 whether or not parental caregiver have let the stigma to influence their emotional state
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9 429 concerns medical staff, related to the treatment of children with T1DM.

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

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

44 444 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
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50 447 younger children with T1DM, parental caregivers will need to dedicate substantial
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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
8
9 454 monitoring, often young children may not have access to these technologies or
10
11 455 compliance may not be possible^[30]. 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.
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19 459 Parental caregivers of children with T1DM also face challenges in transitioning their
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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,
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29 464 children with T1DM and high levels of family conflict have been shown to have
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31 465 poorer blood glucose control and lower overall quality of life^[31 32]. As young children
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33 466 grow into adolescence, these conflicts may become more common or escalate.
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35 467 Khandan (2018)^[33] 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
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39 469 transitioning from "parental responsibility" to "cooperative support." While parents
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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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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
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12 480 of social support. In the majority of cases, discussed in the present study, expenses
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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
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18 483 insurance, but the reimbursement rate varied depending on the type of health
19
20 484 insurance (up to 90%). Similar to the results of other studies^[34], medications and
21
22 485 disposable devices used for long-term treatment place a substantial and ongoing
23
24 486 burden on these families, often affecting housing, employment, and economic
25
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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33 490 Furthermore, the lack of social support and relative social isolation of caregivers,
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35 491 particularly those that reduced hours or left jobs to act as primary caregivers (most
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37 492 common among mothers), was consistently reported in this study. The lack of support
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39 493 systems was apparent from limited family social activities, which often negatively
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41 494 impacted the parental caregiver's emotional state. Compared to other developed
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43 495 regions, China currently has a lack of diabetes nurses in kindergartens and primary or
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45 496 secondary schools. Thus, preschool and school-age children have to assume the
46
47 497 responsibility of diabetes self-management during school hours. In addition many
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49 498 parents in this study reported that blood sugar control was not ideal during school
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51 499 hours, because of self-esteem issues or poor self-control. Therefore, we propose that
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53 500 we should, as a healthcare system, selectively learn from the successful experience of
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3 501 other countries^[35] 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.
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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
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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**

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28 512 This qualitative study employs grounded theory methods to examine the emergent
29
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
33
34 515 parental caregivers as their young children are first diagnosed with T1DM and slowly
35
36 516 gain autonomy for their own chronic disease management with age. This research
37
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
41
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
45
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
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11

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13
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15
16 540 Dr. Huijuan Tong. The manuscript was written by Huijuan Tong and Ling Fan.
17
18

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20
21 542 accordance with the Declaration of Helsinki and was approved by the Institutional
22
23 543 Review Board (IRB) of Shengjing Hospital, China Medical University, Shenyang,
24
25 544 China (Approval no. 2018PS362K). All participants provided written informed
26
27 545 consent prior to participating in interviews.
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29

30 546 **Consent for publication:** Not applicable
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32

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35 548 are included within the article. The datasets used and/or analysed during the current
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39

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45
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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 (Mandarin
 672 Chinese).

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

Characteristic	Interviewee (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%)

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3	Technical school (2-year degree or equivalent)	3 (15%)
4		
5	Bachelor's degree (4-year degree or equivalent)	5 (25%)
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7		
8	Monthly Income (CNY/USD), n (%)	
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10	< 3077/500	5 (25%)
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12	3077-11428/500-1700	9 (45%)
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15	>11428/1700	6 (30%)
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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 (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 emotional regulation and managing parent-child conflict (3) 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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Table Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description	Page
Domain 1: Research team and reflexivity			
Personal 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
Domain 2: study design			

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
Domain 3: analysis and findings			
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