Evaluating fear of hypoglycemia, pediatric parenting stress, and self-efficacy among parents of children with type 1 diabetes and their correlation with glycemic control

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Abstract

Background: This study was designed to determine the level of fear of hypoglycemia (FoH), pediatric parenting stress and self-efficacy in parents of children with type 1 diabetes (T1D).

Methods: In this cross-sectional study, 61 families of children with T1D who had been diagnosed for at least 6 months recruited from "Fabric Diabetes Education Association" in Tehran. Sixty mothers and 41 fathers of 61 children (26 girls, age: 6.0-12.7 years) were assessed using the Hypoglycemia Fear Survey-Parent (HFS-P), Pediatric Inventory for Parents (PIP) and Self-Efficacy for Diabetes Scale-Parent (SED-P) questionnaires. Pearson correlation analysis was used to compute the correlation between HFS-P, PIP and SED-P scores separately for mother and fathers.

Results: Only 8.3% of children had controlled diabetes. Internal reliability of the Persian version of all questionnaires was good. FoH were higher for mothers. Mothers whose children had diabetes for less than two years had significantly lower mean HFS-Behavior subscale (HFS-B) scores than mothers whose children had diabetes for more than two years. There was a positive correlation between fathers’ mean HFS-B score and children’s total insulin dose per day. Parents’ FoH score was positively correlated with increased pediatric parenting stress. Findings also showed considerable emotional distress in 51% of mothers and 29.7% of fathers. Frequency of self-monitoring blood glucose tests (SMBG) correlated negatively with HbA1c.

Conclusion: We concluded that parents with high levels of FoH and stress may benefit from diabetes education. Important implications for education are considering psychological adjustment, recognizing diabetes-related fear and stress in parents, encouraging fathers to become actively involved in the child’s diabetes management and emphasizing the importance of SMBG.

Keywords: Hypoglycemia, Fear, Parenting stress, Self-efficacy, Type 1 diabetes

Introduction

Type 1 diabetes (T1D) is the most common chronic metabolic disorder in children, accounts for 5–10% of the total cases of diabetes worldwide. According to the last International Diabetes Atlas report, more than 500,000 children
Fear of hypoglycemia and stress in type 1 diabetes

developed T1D in 2015 and is suggested to increase by 3% per year worldwide (1). There is limited information about glycemic control, management, and prevalence of diabetic complications in children from Asia (2, 3). Diabetes management and complications in patients from 230 centers in Asia were reported in “Diabcare-Asia”. Only 152 (0.7%) were younger than 18 years, and the mean glycated hemoglobin (HbA1c) level was higher in this younger subgroup (10.7±3.0%) in comparison with the whole cohort (8.6%±2.2%) (2). Dealing with diabetes in children can be challenging, and there are numerous psychosocial and behavioral factors that can affect day-to-day treatment in children. Specially, in children who cannot recognize and verbalize symptoms of hypoglycemia or hyperglycemia, their unpredictable dietary behaviors and physical activity levels make diabetes more difficult to be managed. The International Society for Pediatric and Adolescent Diabetes (ISPAD) Consensus Guidelines stated that diabetes management could be affected by psychosocial factors as the most important influences (4). We hypothesized that there are some factors that affect children’s glycemic control in family framework including (a) parental fear about their child’s hypoglycemia, (b) parental stress associated with caring for a child with diabetes, (c) parental beliefs about their ability to manage their child’s illness (self-efficacy) (5).

Hypoglycemia is an important limiting factor for glycemic control and causes symptoms which may frighten both children and their parents. There is evidence that fear of hypoglycemia (FoH) may be a significant barrier to diabetes management, quality of life and future health outcomes (6-8). Although studies have shown that new insulin regimen and insulin analogs may lower the risk and frequency of hypoglycemic episodes, hypoglycemia remains a problem in children with T1D (9, 10).

Pediatric parenting stresses experienced by parents of children with chronic illness like diabetes are unique compared to general parenting and caregiver stress (11). A large body of pediatric psychology research has focused on mothers, leaving the fathers’ experiences largely unexamined (12, 13). Those studies examining both parents’ adjustments to children’s diabetes have reported varied findings (12); however, one study found that mothers had higher rates of post-traumatic stress than fathers (14). Parents of children with poor diabetes control receiving conventional insulin regimens also report more stress (5). Highest level of parental stress has been reported during the weeks immediately after a child’s diagnosis, which then declines but does not certainly diminish completely over the subsequent year (4).

Parental efficacy in managing their child’s diabetes is negatively related to pediatric parenting stress (5). In asthmatic children, lower parental self-efficacy has been associated with increased asthma-related morbidity (15). Researches on self-efficacy within the diabetes literature are limited (5, 16, 17).

The present study aimed to describe glycemic control and investigate factors that we hypothesized to be associated with, including FoH, emotional distress and self-efficacy in managing diabetes between mothers and fathers of children with T1D. Also, this study was designed to conduct a psychometric investigation and to test the reliability and validity of a Persian version of the Hypoglycemia Fear Survey-Parent version (HFS-P), Pediatric Inventory for Parents (PIP) and Self-Efficacy for Diabetes Scale-Parent version (SED-P) to assess whether these questionnaires can be useful tools for assessment of FoH, parenting stress and self-confidence in managing children’s diabetes (respectively). Moreover, this study examined parent report of the above parameters in a sample of children with T1D with these tools. Another purpose was to evaluate associations of the HFS-P, PIP, and SED-P with children’s glycemic control.

Methods

Participants and Procedure

The study design was cross-sectional and was approved by the Medical Ethical Committee of Iran University of Medical Sciences. Families were identified through a review of the “Gabric Diabetes Education Association” (member of the International Diabetes Federation) database (www.gabric.ir), and then contacted by a member of the research team. Parents were eligible to participate if had a child 6-12 years’ old who had been diagnosed with T1D for at least 6 months. Families were excluded if the child suffered from another disease known to affect growth or another autoimmune disease (e.g. thyroid, celiac). A total of 75 families were approached for the study, and 61 agreed to participate and were eligible (81.33% recruitment rate). Parents and children came to the offices of the Gabcir Diabetes Education Association (GDEA), where they provided written informed consent, then completed a battery of questionnaires, including HFS-P, additional psychological questionnaire including PIP to assess parental stress and SED-P. They also completed a diabetes history questionnaire, including an item to assess the frequency of severe hypoglycemic episodes in the last 3 months. Severe hypoglycemia was defined as children’s hypoglycemia with unconsciousness during which blood glucose was so low that self-treatment was not possible because of mental confusion and external assistance was required. Children’s glycemic control was examined by HbA1c level which was analyzed on whole blood collected in EDTA vacutainer tubes and measured by a designated high-performance liquid chromatography (HPLC) method (Tosoh G7 Automated HPLC Analyzer; Tosoh Bioscience, Grove City, OH, USA). Blood samples for HbA1c analysis were taken on the same day when questionnaires were completed at a laboratory.

Measures and Questionnaires

Questionnaires were translated into Persian for this study using the translation process recommended by the World Health Organization (http://www.who.int/substance_abuse/research_tools/translation/en), which includes forward and backward translation, pre-testing, and cognitive debriefing.

Hypoglycemia Fear: We used the HFS-P to assess parents’ worries and behaviors related to hypoglycemia (18). HFS-P is a 25-item survey that includes a 15-item Worry subscale (HFS-W) and a 10-item Behavior subscale (HFS-
B). The Worry subscale items measure anxiety-provoking aspects of hypoglycemia and the items in the Behavior subscale measure specific behaviors aimed at avoiding hypoglycemia (18). This questionnaire uses a Likert response format ranging from 1 (never) to 5 (always). The HFS-P subscale scores and the total score are obtained by summing the items for respectively the Worry subscale (range 15–75), the Behavior subscale (range 10–50) and the HFS-P total (range 25–125) (7). Other translations of the HFS-P, including English and Norwegian, have previously demonstrated adequate reliability and validity (7, 19). Higher scores indicate higher FoH. In accordance with original HFS-P items, we asked the parents some questions about the frequency of problematic hypoglycemic (refer to the children’s hypoglycemia with consciousness but need parent’s help) episodes during the past 3 months.

Pediatric parenting stress: Parenting distress and stress were assessed using the PIP which measures experiences related to parenting a child with a medical condition (11). The PIP asks parents to rate the frequency and difficulty of 42 events usually reported by parents of children with a chronic illness. The subscales are communications (with child, partner, or healthcare team in 9 items), emotional distress (impact of illness on sleeping quality and mood in 15 items), medical care (carrying out medical regimen in 8 items) and role function (impact of disease on ability to work and caring for other children in 10 items). Responses are scored using two 5-point Likert scales ranging from ‘never’ to ‘very often’ (frequency scale) and ‘not at all’ to ‘extremely’ (difficulty scale). The PIP is scored separately for each of the four domains. There are also two overall total scores comprised of the sum for each of the four domains, yielding total F and total D scores (range: 42–210) to reflect the frequency of stressful events (PIP-F), and the amount of difficulty experienced by parents in managing these events (PIP-D). The PIP has demonstrated strong internal consistency and constructs validity when utilized with parents of children with diabetes (5). Higher scores indicate more frequent problems/more difficulty and increased pediatric parenting stress.

Parent confidence: Parent confidence in managing their child’s diabetes was assessed using the SED-P (20). The SED-P is a 22-item self-report survey that assesses respondents’ confidence in performing daily diabetes management tasks. Participants respond using a 5-point Likert scale ranging from ‘very sure I cannot’ to ‘very sure I can’. Higher scores indicate higher self-efficacy in managing their child’s diabetes.

### Statistical Analysis

Descriptive statistics, correlations, group comparisons, and Cronbach’s alpha reliability coefficient were performed using SPSS 22 (SPSS Inc., Chicago, IL, USA). A p-value less than 0.05 was considered statistically significant. Sample characteristics and HFS-P, PIP and SED-P scores were explained using descriptive statistics including means, standard deviations (SD), and frequency distributions. We used Pearson correlation analysis to compute the correlation between HFS-P, PIP and SED-P scores separately for mother and fathers. Because of the importance of age and duration of diabetes in children, all of the analyses compared across age (≤9 and ≥10 years) and diabetes duration categories (<2 and ≥2 years) as well.

### Results

Internal consistencies of the HFS-P, PIP, and SED-P were calculated using Cronbach’s alpha coefficient for the total scale and each subscale. Cronbach’s alpha for the Persian version of the HFS-P showed good internal consistency for the HFS-W subscale (mothers 0.89; fathers 0.89), the HFS-B subscale (mothers 0.86; fathers 0.86) and the HFS-P total (mothers 0.94; fathers 0.94). The large degree of accordance between the Cronbach’s alpha values for mothers and fathers reinforces the reliability of the Iranian HFS-P. Results found alpha coefficients of 0.93 in both mothers and fathers for the PIP-total frequency domain, 0.96 and 0.95 respectively in mothers and fathers, for PIP-total difficulty domain suggesting the excellent internal consistency for the Persian version PIP. Also, results found alpha coefficients of 0.74 in both mothers and fathers for the SED-P questionnaire.

Parents of 61 children (60 mothers and 45 fathers) completed the questionnaires. Mothers were between 25 and 49 years of age (36.2±5.6), the majority were high school graduates, and 73.3% had a 6-12 years of education. The number of children was 61 with an average age of 9.2 ± 2.0 years (range: 6.1–12.7). The majority of the children were boys (57.4%).

**Table 1.** Children’s demographic and clinical characteristics

| Variable                      | n (%)  | Mean (range) | SD   |
|-------------------------------|--------|--------------|------|
| Age (years)                   | 61     | 9.2 (6.0-12.7)| 2.0  |
| Boys                          | 35 (57.4)|            |      |
| HbA1c                         |        |              |      |
| – Good Control (<7.5%)        | 60     | 9.4 (6.1-13.7)| 1.8  |
| – Poor Control (≥7.5%)        | 55 (91.7)|            |      |
| Duration of diabetes (months) | 61     | 38.7 (6.0-126.0)| 24.5 |
| Total insulin dose per day (units) | 61 | 28.3 (9.0-80.0) | 14.6 |
| Insulin type                  |        |              |      |
| – Human                       | 52 (85.2)|            |      |
| – Analogue                    | 9 (14.8) |             |      |
| Number of Insulin Injections  | 61     |              |      |
| – ≤3/day                      | 50 (82) |             |      |
| – ≥4/day                      | 11 (18) |             |      |
| BG Monitoring Frequency per day|        |              |      |
| – ≤3 times/day                | 33 (56.9)|            |      |
| – ≥4 times/day                | 25 (43.1)|            |      |
| Hypoglycemia (past 3 months)* | 59     | 1.4 (0-36)  | 5.4  |

Note: * Refer to the children’s hypoglycemia with consciousness but need parent’s help

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graduates (65.6%) and 75% did not work outside the home. Fathers were between 30 and 58 years of age (42.0±5.9), and the majority were high school graduates (64%), employed (94.8%) and reported monthly family income under $800 (88.5%).

All parents reported being of Iranian nationality. Table 1 presents the demographic and clinical characteristics of the 61 children. Mean±SD HbA1c was 9.4±1.76 (range: 6.1-13.7) and only 8.3% of children had controlled diabetes by recommended standards (HbA1c< 7.5% (22)). Moreover, HbA1c values was higher in children 10 and older (9.6±1.8) compared to children 9 and younger (9.0±1.7), F (1, 58)= 3.79, p=0.05. There was no significant association between HbA1c and other variables including HFS-P, PIP, and SED-P.

Table 2 summarizes the mean (SD) scores for the HFS-P, PIP and SED-P measures. HFS-P total scores were higher for mothers (51.7±15.2) than fathers (44.8±14), t=2.39, p = 0.022. Mothers whose children had diabetes for <2 years, had significantly lower mean HFS-Behavior subscale (HFS-B) scores than mothers whose children had diabetes for >2 years F (1, 58)= 7.50, p= 0.008. There was a positive correlation between fathers’ mean HFS-B score and children’s total insulin dose per day (r=0.30, p=0.044). PIP scores also differed between mothers and fathers. The mean PIP scores were 128.0 ± 16.4 (frequency) and 108.2±31.3 (difficulty) for fathers. PIP scores in 51% of the mothers and 29.7% of the fathers were above the frequency midpoint cut-off≥ 126, and 51% of the mothers and 40% of the fathers had scores above the difficulty midpoint cut-off ≥ 126 indicating considerable symptomatic emotional distress. SED-P scores did not significantly differ between mothers (79.9 ± 10.8) and fathers (80.5±11.2). SED-P scores were above the suggested midpoint cut-off level of 66 in near all mothers and fathers, indicating acceptable self-efficacy in managing their child’s diabetes. Correlational analyses indicated no significant association between SED-P and parents’ FoH or PIP.

Table 3 summarizes validity analyses. In mothers, both the HFS-W subscale and HFS-P total scores correlated positively with several PIP scores. HFS-W subscale and HFS-P total correlated negatively with PIP-medical care (frequency). Moreover in fathers, HFS-W subscale correlated positively with measures of parenting stress, including PIP-emotional distress (frequency and difficulty), PIP-medical care (difficulty), PIP-role function (frequency and difficulty), PIP-total (frequency and difficulty) and HFS-P total correlated positively with measures of PIP-emotional distress (frequency), PIP-medical care (difficulty), PIP-role function (difficulty), PIP-total (difficulty). No significant associations emerged between parents’ FoH, pediatric parenting stress or self-efficacy and demographic characteristics (age, education, employment, and income). There were no significant associations between parents’ FoH, episodes of children’s hypoglycemia in the

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**Table 2** Mean Hypoglycemia Fear Survey–Parent (HFS), Pediatric Inventory for Parents (PIP) scores and Self-Efficacy for Diabetes Scale- Parent (SED-P) in mothers and fathers of children with Type 1 diabetes (aged 6–12.7 years)

| Score                      | Mothers | Fathers |
|----------------------------|---------|---------|
| n HFS-B subscale           | Mean (range) | Mean (range) |
| 60                        | 26.9 (15-41) | 25.3 (13-42) |
| 60                        | 24.8 (10-50) | 19.7 (1-59)  |
| 60                        | 51.7 (25-100)* | 44.84 (17-36)* |
| 57                        | 24.4 (16-34) | 22.6 (13-31) |
| 56                        | 48.2 (26-68) | 40.8 (22-59) |
| 56                        | 30.9 (23-40) | 26.9 (17-33) |
| 55                        | 24.5 (14-40) | 22.9 (14-33) |
| 56                        | 128.0 (98-172)* | 113.1 (73-151)* |
| 57                        | 23.6 (8-40) | 19.9 (8-32) |
| 55                        | 52.1 (28-74) | 46.4 (15-69) |
| 56                        | 19.5 (8-33) | 16.8 (8-29) |
| 55                        | 26.4 (10-46) | 24.9 (10-38) |
| 56                        | 120.9 (64-186)* | 108.2 (42-152)* |
| 61                        | 79.9 (57-111) | 80.5 (54-110) |

**Table 3** Correlations between Hypoglycemia Fear Survey–Parent version (HFS-P) and Pediatric Parenting Stress (PIP) scores in mothers and fathers of children (aged 6–12.7 years) with Type 1 diabetes

| PIP Score                  | HFS-P subscale | HFS-P total | HFS-W subscale | HFS-W total |
|---------------------------|----------------|-------------|----------------|-------------|
| Stress frequency:         |                |             |                |             |
| • PIP- Communication      | 0.339***       | 0.312**     | -              | -           |
| • PIP- Emotional distress | 0.425**        | 0.440*      | 0.520*         | 0.346***    |
| • PIP- Medical care       | -0.302***      | -0.275***   | -              | -           |
| • PIP- Role function      | 0.278***       | 0.315**     | 0.377***       | -           |
| • PIP- Total              | 0.326**        | 0.338**     | 0.441***       | -           |

| Stress difficulty:        |                |             |                |             |
| • PIP- Communication      | 0.284***       | 0.277***    | 37             | -           |
| • PIP- Emotional distress | -              | 0.286***    | 35             | 0.354***    |
| • PIP- Medical care       | -              | 0.278***    | 36             | 0.463***    |
| • PIP- Role function      | -              | -           | 35             | 0.353***    |
| • PIP- Total              | -              | 0.268*      | 35             | 0.463***    |

Note: *p<0.05, **p<0.01, ***p<0.001. Pearson correlation analysis was used to compute the association between HFS-P and PIP scores

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Discussion

In the current study, the HFS-P, PIP, and SED-P were used to measure worries and behaviors related to FoH, parenting stress and self-efficacy (respectively) in parents of children with T1D in Iran. The Persian version of HFS-P, PIP and SED-P were found to be internally consistent and had good test-retest reliability. This finding suggests that these questionnaires are reliable and valid tools to assess the level of FoH, stress and self-efficacy in a population with diabetes and could provide useful tools for identifying those families who may need diabetes education and support.

Cronbach’s alpha for the Persian version of the HFS-P is comparable with the values reported by Gonder-Frederick et al. (7): 0.91 for the HFS-W, 0.76 for the HFS-B, 0.89 for the HFS-P total, and by Haugstvedt et al. (19): mothers 0.89, fathers 0.89 for the HFS-W; mothers 0.69, fathers 0.69 for the HFS-B and mothers 0.87, fathers 0.84 for the HFS-P total. It should be noted that HFS-P demonstrated mostly good internal consistency in both subscales and total scores but the HFS-B subscale had the lowest internal consistency in both subscales and total scores. Thus it may be that the psychological impact of hypoglycemia in children with T1D. Research suggests that, although fathers are usually not the primary caregiver of the child’s diabetes care, their contribution to the family through insights, knowledge, adjustment, and behavior may be associated with disease management outcomes (12). Of note, the participation rate of fathers was less than mothers in the current study, and only 44 fathers completed all of the items on the HFS-P (one father completed only the Behavior subscale), 35-39 fathers completed all PIP questions, and 42 fathers completed all SED-P questions. By their report, fathers did not answer some of the questions, and 42 fathers completed all SED-P questions. The participation rate of fathers was less than mothers in the current study, and only 44 fathers completed all of the items on the HFS-P (one father completed only the Behavior subscale), 35-39 fathers completed all PIP questions, and 42 fathers completed all SED-P questions. By their report, fathers did not answer some of the questions, and 42 fathers completed all SED-P questions. By their report, fathers did not answer some of the questions, and 42 fathers completed all SED-P questions. By their report, fathers did not answer some of the questions, and 42 fathers completed all SED-P questions. By their report, fathers did not answer some of the questions, and 42 fathers completed all SED-P questions. By their report, fathers did not answer some of the questions, and 42 fathers completed all SED-P questions.
of children’s diabetes is different between mothers and fathers and as Mitchell et al. recommended (16), future research is recommended with a broader range of factors impacted by child health that may contribute to fathers’ psychological health.

Cronbach’s alpha for the Persian version of the PIP and SED-P are comparable with the values reported by Streisand et al. (5): PIP-F= 0.94 and PIP-D= 0.95; by Grey et al. (21): SED-P= 0.88 for adolescents and by Streisand et al. (5): SED-P= 0.89 for parents, respectively. PIP findings also suggest that half of the mothers and nearly 40% of fathers of children with T1D are experiencing considerable parenting stress and symptomatic emotional distress. As reported previously (25), we also found that parents’ FoH was positively correlated with increased frequency and difficulty of pediatric parenting stress. HFS-W subscale and HFS-P total scores correlated significantly with measures of parenting stress. These findings support the validity of the Iranian version of HFS-P and furthermore the association between a higher level of FoH and parental stress emphasizes the need for programs to support and guide both parents. It is very important for diabetes educators to recognize high FoH in parents (27). Although some level of fear is normal and could motivate parents to protect their children from the risk of hypoglycemic episodes, extreme FoH might lead to poorer coping strategies, such as over-eating to prevent hypoglycemia, administering lower doses of insulin and over-feeding children without insulin injection (4). Patton et al. reported a correlation between higher blood glucose concentration and parental behavior aiming to avoid hypoglycemia, whereas the Norwegian study found a positive correlation between the HFS-W and HbA1c (19, 23). Our data showed that many children (91.7%) had suboptimal glycemic control, which could place them at high risk of developing microvascular complications, but did not find any association between parental FoH and glycemic control (HbA1c) maybe because of limited sample size.

None of the FoH, self-efficacy and the parenting stress measures correlated with the number of hypoglycemic episodes in the last 3 months. Perhaps an association would have been identified with a more detailed assessment of hypoglycemia episodes in last 3 months like that conducted in studies by Haugstedt et al. (19) and Patton et al. (23). Others have found that FoH is related to the number of episodes associated with unconsciousness or seizure in the child (18).

Despite the noted findings, children’s glycemic control was negatively correlated with SMBG. This finding replicates the important association reported by Ziegler et al. (28) in a large database study that emphasize the importance of SMBG in better glycemic control again. So the frequency and timing of SMBG should be addressed clearly in diabetes education courses for both parents.

Some limitations of our study are the cross-sectional design, which makes it impossible to explore the causal association between variables and self-report measures, which are vulnerable to a reporting bias. Although we followed suggested scientific procedures when translating HFS-P, PIP, and SED-P into Persian and all of them have demonstrated acceptable reliability and validity in our study, some changes may still be needed based on country culture. For example, only 25% of mothers in this study were employed, and there is a PIP question about “Being unable to go to work”. In addition, questions in HFS-P measure both inappropriate and appropriate behaviors to prevent hypoglycemia, which can be another problem. It would be helpful for researchers using various translations of the same questionnaires to share their cross-cultural experiences in a collaborative manner in order to prepare a culturally comprehensive manual. The sample size was limited, and this could be the reason for the statistically non-significant associations identified between the children’s HbA1c and parents’ FoH, stress and self-efficacy.

Conclusion

In conclusion, the results of this study indicate that the Persian version of the HFS-P, PIP, and SED-P are psychometrically valid and reliable instruments to measure FoH, parenting stress and self-efficacy in managing diabetes in this target group, but may need some cultural changes. Moreover, from the clinical and research perspectives, these questionnaires could be used for identifying those families who are at risk and may need education; and could provide a useful tool for assessing the effect of interventions (27). Also, findings indicate that difficulties in parents’ (especially mothers’) level of high fear of their child’s hypoglycemia correlated with increased frequency and difficulty of parental stress. So diabetes education and counseling, problem-solving and stress management training for parents could prepare them to manage their child diabetes. Based on findings from the current study, important implications for diabetes education are: considering psychological adjustment, identifying diabetes-related fear and stress in parents of children with T1D, encouraging fathers to become more involved in the child’s diabetes management to reduce mothers feeling overstressed. Because improving health outcomes of children with diabetes is a multifaceted process, the results of this study suggest that targeting parental FoH, stress, and self-efficacy may be helpful components of structured education courses in this population.

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Conflicts of Interest

The authors have no conflict of interest.
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