

Original Article

Parental fear of hypoglycemia: young children treated with continuous subcutaneous insulin infusion

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Background: The objective of this study was to examine the association between parental fear of hypoglycemia and average daily blood glucose control of young children with type 1 diabetes receiving continuous subcutaneous insulin infusion (CSII). We hypothesized that parental fear of hypoglycemia would correlate positively with children's average daily blood glucose control.

Methods: Twenty-four families of children with type 1 diabetes who were receiving CSII were recruited from a pediatric hospital. Children had a mean age of 5.7 ± 1.8 yr (range 2–8 yr) and were evenly split on gender. Parents completed a modified version of the Hypoglycemia Fear Survey – Parents of Young Children (HFS-PYC), a measure designed to assess fear and avoidance behaviors associated with hypoglycemia. Blood glucose was assessed for the 2 wk following completion of the HFS-PYC using a standard home blood glucose meter.

Results: Parents of young children obtained a mean total HFS-PYC score of 81 ± 14.1 (possible range 26–130), suggesting a moderate level of fear. The HFS-PYC was found to be internally consistent and had good test–retest reliability. For parents of young children receiving CSII, fear of hypoglycemia correlated positively with children's mean daily blood glucose levels ($r = 0.41$, $p = 0.05$).

Conclusions: Parents of young children with type 1 diabetes who are receiving CSII report significant fear of hypoglycemia. Parental fear of hypoglycemia may be a barrier to prevent optimal glycemic control.

**Susana R Patton^a,
Lawrence M Dolan^{b,c},
Racquel Henry^d and
Scott W Powers^{c,d}**

^aDivision of Child Behavioral Health, Department of Pediatrics and Communicable Diseases, C.S. Mott Children's Hospital and the University of Michigan, Ann Arbor, MI, USA;

^bDivision of Endocrinology, Department of Pediatrics, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, USA; ^cDepartment of Pediatrics, University of Cincinnati College of Medicine, Cincinnati, OH, USA; and ^dDivision of Behavioral Medicine and Clinical Psychology, Department of Pediatrics, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, USA

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Corresponding author:
Susana R. Patton, PhD
Division of Child Behavioral Health
University of Michigan
1924 Taubman Center
Box 0318

1500 E Medical Center Drive
Ann Arbor, MI 48109-0318
USA.

Tel: (734) 936-4220;

fax: (734) 936-6897;

e-mail: susanap@med.umich.edu

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Achieving optimal glycemic control is a fundamental goal of treatment in type 1 diabetes mellitus. Findings of the Diabetes Control and Complications Trial demonstrated that optimizing glycemic control can decrease the development and severity of micro- and macrovascular complications in adolescents and adults with type 1 diabetes (1, 2). Better glycemic control can be achieved through intensive insulin management delivered via multiple daily injections or

through the use of a continuous subcutaneous insulin infusion (CSII) pump. However, because early methods of intensive managements were associated with greater risk of hypoglycemia, intensive therapy was not initially recommended for all patients with type 1 diabetes.

Recent improvements to intensive management, including advances in insulin pump technology and the use of insulin analogs, have decreased the risk of

hypoglycemia. Despite this, for young children with type 1 diabetes, movement to intensive management and, specifically, the use of a CSII pump has been controversial. For young children, the advantages of CSII are clear: greater flexibility with regards to the timing and amount of carbohydrates eaten, improved insulin management during times of high and low activity, ability to provide smaller doses of insulin, and a decrease in the number of insulin injections. Yet the possible increased risk of hypoglycemia is a striking disadvantage for this patient population, where frequent episodes of hypoglycemia could result in neurocognitive compromise (3). Recently, several small studies have demonstrated the safety of using CSII in young children with type 1 diabetes, despite the increased risk of hypoglycemia (4–7). These studies may help to make the use of CSII more widespread among families of young children with type 1 diabetes.

While research is suggesting that CSII may be used safely in young children without significantly increasing their risk of hypoglycemia, no study has examined parents' fear of hypoglycemia in this patient population or examined the relationship between parents' fear of hypoglycemia and children's blood glucose levels. Fear of hypoglycemia has been well documented in adult and adolescent patients with type 1 diabetes, as well as in mothers of preadolescents with type 1 diabetes (8–11). Moreover, research suggests that patients who report fear of hypoglycemia may actively attempt to avoid hypoglycemia by maintaining higher than optimal blood glucose levels (10, 11). If parents of young children with type 1 diabetes who are receiving CSII therapy also fear hypoglycemic events, it is possible that this fear could affect how they manage their child's diabetes. Therefore, the objectives of this study were to assess the reliability of a modified form of the Hypoglycemia Fear Survey (HFS) in parents of young children receiving CSII and to examine the association between parents' fear of hypoglycemia and children's average daily blood glucose control for a sample of young children receiving CSII. We anticipated that parents who report a high level of fear of hypoglycemia may be predisposed to maintain their children at higher than optimal blood glucose levels so as to avoid episodes of hypoglycemia. Thus, our primary hypothesis for this study was that in young children, parents' fear of hypoglycemia would correlate positively with children's average daily blood glucose.

Methods

Participants

Families who participated in this project were recruited from the Pediatric Diabetes Center (PDC)

at Cincinnati Children's Hospital Medical Center (CCHMC). Families were eligible to participate if they had a child between 2 and 8 yr old who had a confirmed diagnosis of type 1 diabetes for at least 6 months and the family had at least 3 months experience using CSII. Based on these criteria, a preliminary list of 28 eligible families was obtained from the PDC and 24 consented to participate in the study, reflecting a recruitment rate of 86%. Families who elected not to participate reported concern with the extra time needed to complete the study as their primary reason for declining participation. No difference was found in the mean age of children of families that declined participation (5.3 ± 1.5 yr) when compared to children who participated (5.7 ± 1.8 yr).

Procedure

Families were contacted by a member of the research team via letter, telephone call, or in clinic solicitation. Families that agreed to participate scheduled an enrollment visit with the research team during which parents provided written informed consent, completed study questionnaires, and learned how to use a standardized home blood glucose meter (one participant used a compatible personal blood glucose meter). Approximately 2 wk after enrollment, families returned to the clinic for a follow-up study appointment, during which they completed one study questionnaire and data were downloaded from the home blood glucose meter. Families received a \$20 gift card to Toys R' Us for their participation and were allowed to keep the blood glucose meter they received for the study. This study was reviewed and approved by the CCHMC Institutional Review Board.

Dependent measures

Children's average daily blood glucose levels. To measure children's average daily glycemic control, 23 families were given one FreeStyle (Abbott Laboratories, Abbott Park, IL, USA) home blood glucose meter to test their child's blood glucose during the study. One family elected to use a comparable but newer glucose meter (Flash, Abbott Laboratories), which they had recently received. Families were instructed to test their child's blood glucose via a finger stick at least four times daily for 2 wk using the study meter. In addition, families were asked to use the study meter for all blood glucose tests that were conducted away from home during the 2-wk period. Although all the families agreed to use the study meter exclusively for 2 wk, several families reported episodes of forgetting to bring the study meter with their child. In these situations, blood glucose levels that were not

collected on the study meters were considered missing. While families were not given specific instructions regarding the timing of blood glucose tests, the majority of tests appeared to be preprandial and 21% of measures were gathered at nighttime (defined as between 21:00 and 05:30 hours). On average, children had 95.7 ± 39.8 blood glucose readings (6.2 ± 2.8 readings/d) for the study period.

Children's average blood glucose control. To assess children's average blood glucose control, hemoglobin A1c (HbA1c) data were gathered from a medical chart review. For this study, children's HbA1c at the time of study enrollment and 3 months after study enrollment were collected. We elected to collect the HbA1c value from 3 months after study enrollment in order to capture children's average blood glucose levels at the time of study participation.

Parents' fear of hypoglycemia. Parents' fear of hypoglycemia was assessed using a modified form of the Hypoglycemic Fear Survey – Parent (HFS-P) (8, 9). The HFS-P is a valid 25-item questionnaire, which measures parent's fear of hypoglycemia in their children (9). The HFS-P is divided into two subscales, which independently assess parents' behaviors related to preventing an episode of hypoglycemia and their worry that their child may experience an episode of hypoglycemia. For each item, parents are asked to report how often the item is true for them using a 5-point Likert scale (1 = never to 5 = very often). The HFS-P yields an individual subscale score for each of the Behavior and Worry scales and a Total Score, with higher scores indicating greater fear of hypoglycemia. For the current study, the HFS-P was modified to be specific to the issues of parents of young children with type 1 diabetes and named the Hypoglycemia Fear Survey – Parents of Young Children (HFS-PYC). In addition, one question from the original HFS, which related to fear of having a hypoglycemic event while driving, was added to the HFS-PYC and was modified so that it described the parents' fear that their child might have a low blood glucose while the parent was driving (8).

Children's demographic information. Family demographics were obtained by parents' self-report. Parents were asked to provide information about their child (e.g., gender, date of birth, ethnicity), themselves (e.g., relationship to the child, age, ethnicity), and their family (e.g., number of children, parents' highest completed education level, and parents' current employment). To estimate families' socioeconomic status, parents' level of education and current employment were recorded and analyzed using the Hollingshead Four-Factor Scale (A. Hollingshead, unpublished thesis). All other data were used to describe the sample.

Children's medical history. Children's frequency of hypoglycemia was assessed via parent-report on a brief medical history form. In this form, parents were asked

to self-report the age when their child was first diagnosed with type 1 diabetes. In addition, parents were asked to report on their child's frequency of hypoglycemic events within the past 6 months and if their child had experienced a seizure because of hypoglycemia. For this form, parents were to consider a hypoglycemic event to be any time their child had a blood glucose level of 60 mg/dL or less. Although many families define hypoglycemia based on symptoms, we decided not to use symptoms in our definition because the occurrence and severity of symptoms are very individual and may be difficult to measure reliably.

Data analyses

All data were analyzed using spss statistical software (2005 version). Sample characteristics and parents' HFS-PYC scores were examined according to means, standard deviations, and frequencies. To assess the reliability of the HFS-PYC, data on the internal consistency and test-retest reliability were obtained. To test the primary hypothesis that parents' fear of hypoglycemia would correlate positively with children's average daily blood glucose levels, two-tailed Pearson product-moment correlations were used. Two-tailed Pearson correlations were also used to explore associations between parents' HFS-PYC scores and descriptive data (e.g., child age, length of time with type 1 diabetes). However, because these correlations were considered exploratory and were completed after examining the primary associations, we elected not to correct for multiple correlations. *Post hoc* correlations suggested no relationships between children's average daily blood glucose and their age and disease duration. Finally, to aid in interpreting the findings of this study, the authors compared fear of hypoglycemia in parents of young children with type 1 diabetes to HFS scores from a published study of mothers' of older children with type 1 diabetes (9). To conduct these analyses, each score was first divided by the number of items in the scale to obtain an adjusted score that controlled for differences in the number of questionnaire items (e.g., 25 items in the published sample and 26 items in the current sample). The adjusted scores were then compared using a series of one-sample *t*-tests.

Results

Participants

Table 1 presents descriptive statistics and clinical data for the 24 children who participated in this study. Children had a mean age of 5.7 ± 1.8 yr and a mean time since diagnosis of 3.1 ± 1.3 yr. There were 12

Table 1. Demographic and health information

Variable	M	SD
Age (yr)	5.7	1.8
Blood glucose level (mg/dL)	206	14
HbA1c (at study enrollment)	8.3	0.87
HbA1c (3 months post-study enrollment)	7.8	1.1
BMI	16.6	1.8
z-BMI	0.39	1.1
	Frequency	%
Gender		
Boy	12	50
Girl	12	50
Race		
White	23	96
Non-White	1	4
Parent respondent		
Mother	20	83
Father	4	17
Socioeconomic status*		
I	0	0
II	1	4
III	7	29
IV	12	50
V	4	17
Marital status		
Married	22	92
Frequency of hypoglycemia (<60 mg/dL)		
Once per day	1	4
1–2/wk	8	33
3–5/wk	12	50
Once per month	2	9
Once every few months	1	4
History of hypoglycemic seizure		
Yes	6	25
No	18	75

HbA1c at study enrollment.

BMI, body mass index; HbA1c, hemoglobin A1c; M, mean; SD, standard deviation.

*The Hollingshead Four-Factor Scale is measured from I (lowest level) to V (highest level).

boys and 12 girls in the sample. Children in this sample had a mean daily blood glucose level of 206 ± 14 mg/dL. The target blood glucose range for children in this sample was between 70 and 200 mg/dL. Overall, children averaged 51 ± 13% of blood glucose tests within the target range, 5 ± 3% of tests below the target range, and 44 ± 14% above the target range. Children had a mean HbA1c of 8.3 ± 0.83 at study enrollment and 7.8 ± 1.1 after 3 months of study enrollment (reference range 3.5–6.3%). Children's HbA1c levels 3 months after study enrollment correlated with their average number of blood glucose tests performed each day during the 2-wk study period ($r = -0.49, p < 0.05$), while a statistical trend was found when correlating children's HbA1c levels with their average blood glucose levels for the study ($r = 0.38, p = 0.07$). Children's HbA1c levels 3 months after study enrollment correlated with the percentage of blood glucose tests that were within the target range ($r = -0.49, p < 0.05$).

With respect to fear of hypoglycemia, parents obtained a mean Total Score on the HFS-PYC of 81 ± 14.1 (possible range 26–130). Parents' mean Worry and Behavior subscale scores were 44.3 ± 11.1 (possible range 16–80) and 33.7 ± 5.3 (possible range 10–50), respectively. Parents' HFS-PYC scores did not correlate with children's age, time since diagnosis, or average number of blood glucose tests performed each day. Interestingly, negative associations were found between families' level of socioeconomic status and parents' Total and Worry Scores of the HFS-PYC ($r = -0.52, p < 0.01$, and $r = -0.47, p < 0.05$). While parents' Total Scores on the HFS-PYC were not related to their reporting of how frequently their child experienced a hypoglycemic event, among children who had had a hypoglycemic seizure, comparisons revealed a statistical trend in parents' HFS-PYC Worry Scores, suggesting that parents of young children who have had seizures may worry more about hypoglycemia than parents of children who have not had a seizure (50.7 ± 12.6 and 41.7 ± 9.6, respectively). With respect to children's HbA1c, only parents' HFS-PYC Behavior Score was found to correlate ($r = 0.42, p = 0.04$) with children's HbA1c 3 months after study enrollment, suggesting that parents of children with higher average blood glucose levels endorsed frequent use of behaviors aimed at preventing hypoglycemia.

Table 2 identifies specific items on the HFS-PYC that were endorsed by parents as common strategies they might use to avoid hypoglycemia or frequent worries about hypoglycemia. The most common strategies endorsed by parents to prevent hypoglycemia were 'carrying fast-acting sugar' (100%), 'checking blood sugar often when attending a long event' (75%), 'avoiding being away from the child when his/her sugar might go low' (67%), and 'feeding the child at the first signs of hypoglycemia' (63%). The most common worries reported by parents specific to hypoglycemia were 'feeling the child will have a low blood sugar while asleep' (63%) and 'the child having a low blood sugar when away from the parent' (46%).

Reliability

Internal consistency of the HFS-PYC was calculated using Cronbach's alpha coefficient for the Total scale and each subscale. Results found alpha coefficients of 0.86, 0.62, and 0.89 for the HFS-PYC Total, Behavior, and Worry Scores, respectively, suggesting that the measure retained good internal consistency. The 2-wk test-retest reliability of the HFS-PYC was 0.91 ($p < 0.001$), 0.73 ($p < 0.001$), and 0.91 ($p < 0.001$) for the Total, Behavior, and Worry Scores, respectively, indicating good stability of scores for the HFS-PYC.

Associations between parents' fear of hypoglycemia and Children's average daily blood glucose levels

Next, analyses sought to examine associations between parents' fear of hypoglycemia and children's average daily blood glucose levels. Our primary analyses sought to correlate children's average daily blood glucose levels with parents' HFS-PYC scores, while secondary analyses examined associations between parents' HFS-PYC scores and the percentage of blood glucose tests that were within, below, and above the target range. Consistent with our hypothesis, findings revealed a significant positive association between parents' Total HFS-PYC scores and children's average daily blood glucose control ($r = 0.41$, $p = 0.05$), suggesting that among parents of young children receiving CSII, parents of children with higher average blood glucose levels reported greater fear of hypoglycemia. Furthermore, a statistical trend was found between parents' Worry Score and children's daily blood glucose control ($r = 0.39$, $p = 0.06$). While parents' reporting on the Behavior scale of the HFS-PYC did correlate with children's HbA1c levels for blood glucose values associated with the time of the study, no correlation was found between parents' HFS-PYC Behavior Scores and children's average daily blood glucose levels. When data were examined according to the percentage of blood glucose tests that were within, below, or above the target range of 70–200 mg/dL, generally similar findings were obtained. Parents' HFS-PYC scores correlated negatively with the percentage of tests within the target range (Total: $r = -0.54$, $p < 0.05$; Worry: $r = -0.47$, $p < 0.05$; and Behavior: $r = -0.43$, $p < 0.05$) and positively with the percentage of tests above the target range (Total: $r = 0.54$, $p < 0.05$; Worry: $r = 0.45$, $p < 0.05$; and Behavior: $r = 0.47$, $p < 0.05$). There were no significant correlations between parents' HFS-PYC scores and the percentage of blood glucose tests that were below the target range.

One-sample comparisons of parents' HFS scores

Finally, analyses sought to compare fear of hypoglycemia for parents of young children with type 1 diabetes to mothers of school-age children with type 1 diabetes using adjusted HFS scores (9). Findings revealed no difference in the adjusted Total Scores of the HFS for parents of young children (3.11 ± 0.5) and mothers of school-age children (2.94 ± 0.6). Likewise, no differences were found in the adjusted Behavior (3.37 ± 0.5 and 3.32 ± 0.6 , parents of young children and mothers of school-age children, respectively) and Worry (2.77 ± 0.7 and 2.68 ± 0.8 , parents of young children and mothers of school-age children, respectively) Scores.

Discussion

Current research suggests that CSII therapy can be used safely in young children with type 1 diabetes, despite the increased risk of hypoglycemia found in early studies conducted before the widespread use of insulin analogs (4–7). However, because of the risk of neurocognitive compromise related to frequent episodes of hypoglycemia in young children, many parents may still be concerned about using this technology (3). No study has specifically examined parents' fear of hypoglycemia in young children with type 1 diabetes who are receiving CSII therapy.

In this study, the HFS-PYC overall demonstrated good internal consistency and test–retest reliability in parents of young children receiving CSII. The Behavior subscale of the HFS-PYC had the lowest measure of internal consistency and test–retest reliability, which was likely because of a difference in the number of items for this subscale (e.g., 10 vs. 16 items) and lack of variability in parent reporting. The results from this cross-sectional study of parents' fear of hypoglycemia in families of young children receiving CSII therapy found that fear of hypoglycemia is a frequent concern for these families and may be highest among parents of children with higher average blood glucose levels vs. lower levels. No differences were found when comparing fear of hypoglycemia in parents of young children and mothers of school-age children with type 1 diabetes (9). Consistent with the literature, parents' fear was not associated with child demographic variables, such as age, time since diagnosis, number of blood glucose tests performed per day, or HbA1c levels (9). There was also no association between parents' fear of hypoglycemia and the number of hypoglycemic episodes reported by parents (9). In contrast to previous research, the current study found a negative association between parents' fear of hypoglycemia and families' socioeconomic level, suggesting that higher socioeconomic status may protect parents from greater levels of fear of hypoglycemia. The current study also found a positive association between parents' HFS-PYC Behavior Scores and children's HbA1c levels, suggesting that parents of young children receiving CSII may voluntarily engage in diabetes management behaviors that prevent hypoglycemia and elevate children's blood glucose levels. Indeed, item-level analysis of the HFS-PYC suggested that parents may frequently feed their child if they feel their child's blood glucose is getting low. These analyses also suggested that parents may be vigilant about hypoglycemia and test their child's blood glucose often or avoid being away from their child if there is a concern that his/her blood glucose could drop. However, because children's HbA1c levels were collected for the 3 months subsequent to study enrollment, it is possible that

Table 2. Items of the HFS-PYC endorsed by parents as occurring 'often' or 'very often'

HFS-PYC items	% Endorsed
Behavior scale	
1. Feed my child large snacks at bedtime	17
2. Avoid allowing my child to be away from me when his/her sugar is likely to be low	67
3. Try to run a little high to be on the safe side	13
4. Keep my child's sugar higher when he/she will be away from me	21
5. Feed my child as soon as I feel or see the first signs of low blood sugar	63
6. Reduce my child's insulin when I think his/her blood sugar is low	29
7. Keep my child's blood sugar higher when I know he/she is planning to be at a long event (e.g., school, party)	29
8. Always carry fast-acting sugar	100
9. Don't allow my child to play excessively when I think his/her blood sugar is low	42
10. Check my child's blood sugar often when he/she is planning to be at a long event (e.g., school, party)	75
Worry scale	
11. Not recognizing that my child is having a hypoglycemic event	33
12. Not having food or fruit juice with me for my child	17
13. Having my child dizzy or pass out in public	17
14. Feeling that my child will have a low blood sugar while he/she is asleep	63
15. My child embarrassing him/herself in front of friends/family in a social situation	8
16. My child having a low blood sugar when he/she is away from me	46
17. My child being disoriented	25
18. My child losing control	17
19. No one being around to help my child during a hypoglycemic event	38
20. My child making a mistake or having an accident at day care/school	17
21. My child getting a bad evaluation at day care/school because of something that happens when his/her sugar is low	25
22. My child having seizures	38
23. My child developing long-term complications from frequent low blood sugars	33
24. My child feeling light headed or faint	29
25. My child having an insulin reaction	25
26. My child having a hypoglycemic event while I'm driving	25

HFS-PYC, Hypoglycemia Fear Survey – Parents of Young Children.

parents' completion of the HFS-PYC may have sensitized them to episodes of low blood glucose and affected how they manage their child's diabetes. Thus, the reader is cautioned against overinterpreting this relationship.

This is the first study to examine parents' fear of hypoglycemia in young children (less than 8 yr old) with type 1 diabetes who are exclusively managed via CSII therapy. In young children, parents assume the full burden of caring for their child's diabetes. This job is complicated by normal developmental limitations of this age range, including limited cognitive insight into physical symptoms, limited language skills, and increasing independence seeking and behavioral resistance (12). Moreover, because young children with type 1 diabetes are frequently more insulin sensitive than older children, parents of young children are frequently advised to be vigilant with respect to monitoring their child's diet and behavior and checking their child's blood glucose levels (13). As a result, the vigilance needed for parents to maintain their young children in optimal glycemic control may contribute to parents' heightened fear of hypoglycemia. While some level of fear of hypoglycemia is

adaptive and could help parents to protect their children from hypoglycemic episodes, higher levels of fear may lead to poorer coping strategies, such as administering lower doses of insulin, feeding children without administering insulin, or overtreating episodes of low blood glucose levels. These behaviors, in turn, may lead to higher than optimal blood glucose levels. Recent research suggests that prolonged and frequent episodes of hyperglycemia may also be associated with neurocognitive compromise in young children (14), which underscores the importance of teaching families to maintain their children's blood glucose levels close to the normal range. It is also possible that parents who have greater fear of hypoglycemia may regularly overfeed their children, which could over time lead to weight gain and greater insulin resistance. To achieve the best possible control, families using CSII are required to adhere to the insulin prescriptions and target blood glucose ranges suggested by their health care provider. Thus, in situations where children have higher than optimal blood glucose levels and/or parents report feeding their child frequent snacks or large meals, health care providers should assess parents' fear of hypoglycemia

and help parents use more adaptive strategies for coping with their fear and managing their child's diabetes. Scheduled self-monitoring of children's blood glucose levels and recording of these levels in a log book is one adaptive strategy that parents could be taught to use to manage their child's diabetes and their fear, as this strategy could lead to both accurate measurement of children's blood glucose levels as well as identification of patterns of behavior that may precipitate low blood glucose episodes. Similarly, in situations where parents are overfeeding their child, they may benefit from counseling by registered dietician and development of an individualized meal plan with specific carbohydrate targets for meals and snacks.

In this study, we report on parents' fear of hypoglycemia in young children with type 1 diabetes who are receiving CSII. It should be noted that the data were obtained from a relatively small sample of families of young children with type 1 diabetes who were primarily White, married, and from the middle to upper middle class. While the sample of families recruited for this study is representative of the clinic population and the communities from which it was drawn, our results may not generalize to patient samples drawn from a diverse population. In addition, our study used a parent-report questionnaire to measure parents' fear of hypoglycemia. While the HFS-PYC and the original HFS-P have demonstrated acceptable reliability (9), self-report measures are vulnerable to a reporting bias. Therefore, caution is advised in the interpretation and application of these findings, as it is possible that parents' reporting on the HFS-PYC could have been influenced by elements of social desirability.

For parents of young children with type 1 diabetes who are receiving CSII therapy, fear of hypoglycemia appears to be a significant source of concern and may predict poorer blood glucose control for many children. While it is important that parents' understand the seriousness of hypoglycemia and the need to avoid hypoglycemic episodes, if their fear is too great, parents could begin to use more maladaptive strategies for managing their anxiety, which ultimately could affect children's long-term health outcomes. The findings of this study suggest that health care providers may need to assess for fear of hypoglycemia in parents of young children receiving CSII. Use of the HFS-PYC could be incorporated into the clinical care regimen to assess and prompt discussion of this topic. The measure takes less than 10 min to complete and can be readily scored within a clinical context. Future research should replicate our findings regarding the reliability and usefulness of the HFS-PYC. Also, studies are needed that focus on developing interventions to help parents of young children with type 1 diabetes learn to deal effectively with hypoglycemic events and address parents' fear of hypoglycemia.

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