REVIEW

Assessing fear of hypoglycemia in children with Type 1 diabetes and their parents

Linda Gonder-Frederick[†1], Maren Nyer[2], Jaclyn A Shepard[1], Karen Vajda[1] & William Clarke[3]

Practice Points

- Hypoglycemia management presents unique challenges for families of children with Type 1 diabetes.
- Both children with Type 1 diabetes and their parents can develop fear of hypoglycemia (FoH).
- FoH can be reliably assessed using versions of the Hypoglycemia Fear Survey (HFS) developed for children with Type 1 diabetes and their parents.
- The HFS for children appears to reliably report the level of FoH in children as young as 6–8 years old.
- Parental FoH is likely to be higher when their child has experienced a particularly severe or traumatic episode.
- Children's FoH is likely to be higher when the child has experienced frequent hypoglycemia and/or has a higher level of trait anxiety.
- High levels of FoH may be, but are not always, associated with increased hypoglycemia avoidance, which can lead to increased hyperglycemia and poorer diabetes control.
- FoH should be assessed in children with Type 1 diabetes and their parents on a routine basis in order to identify families who may need support or intervention.

SUMMARY This article summarizes the literature on fear of hypoglycemia in pediatric Type 1 diabetes and the assessment of this fear in both children with Type 1 diabetes and their parents. The most common instrument for assessing fear of hypoglycemia in this population is the children's and parent's versions of the Hypoglycemia Fear Survey (HFS), although studies using other assessment measures are also reviewed. Studies using this survey have identified variables contributing to fear of hypoglycemia in children with Type 1 diabetes and their parents, such as history of frequent or traumatic hypoglycemia, as well as trait anxiety. In addition to this summary of the literature, new data are presented supporting the reliability of hypoglycemic fear assessment in younger children and comparing fear of hypoglycemia in children in different age groups (6–18 years old) and their parents. Also reviewed are studies investigating the relationship between fear of hypoglycemia and diabetes control, which have yielded inconsistent results. Given the potential importance of fear of hypoglycemia in pediatric diabetes, there has been limited research in this area.

[1]Department of Psychiatry & Neurobehavioral Sciences, University of Virginia, VA, USA
[2]Department of Psychiatry, The Massachusetts General Hospital/Harvard Medical School, Boston, MA, USA
[3]Department of Pediatric Medicine, University of Virginia, VA, USA
[†]Author for correspondence: lag3g@virginia.edu

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The two main purposes of this article are as follows: first, we will review the currently available literature on fear of hypoglycemia (FoH) in one youth with Type 1 diabetes and the measures used in research to quantify this construct. While most of the studies reviewed have used pediatric versions of the Hypoglycemia Fear Survey (HFS), which is described in detail later, research employing other measures of FoH are also included. In addition, because FoH is also highly relevant to parents of youth with Type 1 diabetes, this review incorporates the available findings on FoH in mothers and fathers. This article is not intended to be a meta-analysis or even a systematic review of the literature, which would require a thorough analysis of the methodological quality and possible reporting biases of the included studies. Rather, the goal is to review the current state of knowledge about FoH in pediatric Type 1 diabetes and the measures that are most commonly used to assess the level and impact of fear in this population. The method for identifying articles for inclusion began with searches on PubMed, Elsevier, Wiley Online Library, Science Direct and Springer Link, using the search terms 'fear of hypoglycemia', 'hypoglycemia fear survey', 'hypoglycemia fear measures', 'assessment of hypoglycemia fear', 'hypoglycemia worry', and 'hypoglycemia concern'. This search yielded 107 articles on FoH, 24 of which addressed FoH in pediatric Type 1 diabetes, none of which were excluded in this review.

In addition to providing a descriptive review, this article also presents new findings regarding the assessment of FoH in children at different age levels and in parents whose Type 1 children differ in age and developmental stage. By aggregating separate datasets from previous studies in our laboratory that included measures of FoH in Type 1 youths and their parents, it was possible to investigate several important questions that require information on a large number of children with a broad range in age. These included questions concerning age effects on level of FoH in children and adolescents, as well as the ability of younger children to provide reliable and valid self-reports of this fear. Before these findings are presented, this article will review the existing literature on pediatric FoH, beginning with an exploration of the problem of hypoglycemia in Type 1 diabetes and it is especially problematic impact on Type 1 diabetes in children.

The problem of hypoglycemia in Type 1 diabetes

For individuals with Type 1 diabetes, hypoglycemia is the most common acute side effect of insulin therapy and serves as one of the major barriers to optimal glycemic control [1]. Hypoglycemia is characterized by abnormally low blood glucose (BG) levels that can trigger multiple negative physiological outcomes. These include unpleasant adrenergic symptoms (e.g., sweating, shaking and heart palpitations) related to hormonal counter-regulation and neuroglycopenic symptoms (e.g., dizziness, lethargy, slurred speech and mental confusion) caused by an inadequate supply of glucose to the brain. Episodes of severe hypoglycemia (SH) can result in potentially life threatening consequences, including loss of consciousness, seizure, accidents, physical injury and in the most severe cases, death [2]. Risk for hypoglycemia is known to vary based on a number of factors, including glycemic control, impaired awareness of hypoglycemia, age, duration of diabetes and history of SH [3,4]. Surveys of adults with Type 1 diabetes suggest an annual prevalence rate of SH of approximately 30–40% [3]; however, these rates may be an underestimate owing to the tendency to exclude patients with frequent SH from many clinical trials [3].

The problem of hypoglycemia in pediatric Type 1 diabetes

In children and adolescents, reported incidence rates of hypoglycemia vary and remain difficult to ascertain, largely due to the lack of a standardized definition of hypoglycemia and differentiation of symptoms across studies [5]. However, based on early research, youths with Type 1 diabetes are considered at increased risk for experiencing SH episodes compared with adults [6]. In the Diabetes Control and Complications Trial (DCCT), adolescents had significantly more SH events than adults regardless of type of treatment (i.e., conventional or intensive). Incidence may be even higher in younger children. A prospective study of 657 youths with Type 1 diabetes found higher rates of hypoglycemia in children under the age of 6 years compared with those older than 6 years [7]. Although episodes of SH were rare in the year following diagnosis, over the course of this 3-year study, 8.5% of youths experienced SH and 26.9% experienced moderate episodes of hypoglycemia. Youths in better metabolic control, as measured by glycosylated

hemoglobin (HbA1c) levels, were at increased risk for both moderate and severe hypoglycemia compared with those in poorer control. This relationship between better control and increased hypoglycemia presents a significant challenge for youths and their parents in attempting to achieve optimal management of BG levels.

In youths, as in adults, hypoglycemic episodes are typically triggered by behaviors that result in a mismatch in insulin, food and physical activity. Regulation of food intake and physical activity in relation to insulin concentrations are especially problematic in children and adolescents. Eating can be unpredictable in the amounts and timing of carbohydrate consumption, such as in toddlers and preschool children who can resist food intake at times and adolescents who may engage in more snacking and social food consumption. Physical activity can also occur unpredictably in youths. The most common adverse consequence of exercise in individuals with Type 1 diabetes is falling glucose levels [8], therefore vigorous physical activity is a major risk factor for significant hypoglycemia [9]. Unfortunately, some youth and their parents may attempt to decrease this risk by overconsumption of carbohydrates before, during and after exercise [10].

For youths, the possible negative effects of SH on neurocognitive functioning also make hypoglycemia especially problematic. There is mixed evidence on whether recurrent episodes of SH have long-lasting negative cognitive effects in both adults and children with Type 1 diabetes [11,12]. However, patients diagnosed at a younger age (e.g., 4 or 5 years of age), as well those from lower socioeconomic backgrounds, may be at greater risk [13–15]. However, these findings are poorly understood owing to the number of confounding variables in addition to SH that may affect cognitive function in children with Type 1 diabetes, including duration of diabetes and frequency of diabetic ketoacidosis. Meta-analyses have concluded that children with Type 1 diabetes experience mild cognitive impairments compared with nondiabetic controls, specifically on measures of general intelligence, attention, visuospatial abilities and motor speed [16,17]. But these differences may be related to hyper- not hypo-glycemia [12,18]. In addition, there is evidence that SH may be related to deficits in short-term verbal memory, but results are inconsistent and warrant further research [16,17,19].

Research on continuous glucose monitoring (CGM) has highlighted the fact that nocturnal hypoglycemia is particularly worrisome for children, as it can lead to delayed treatment or may go undetected altogether [20]. Early CGM studies found high incidence rates of nocturnal hypoglycemia in the pediatric population, with estimated rates ranging from 14–47% [21,22]. In addition to CGM studies, the DCCT found that more than half of SH episodes occurred during the night, and Davis and colleagues reported that 75% of youth's SH episodes occurred at nighttime [6,7]. The risk of nocturnal hypoglycemia is particularly concerning for parents, who actively engage in night time management of their children's diabetes. For example, parental anxiety about nocturnal hypoglycemia often results in increased monitoring of BG levels overnight, which can cause increased parenting stress and anxiety [23], and in extreme cases may lead parents to keep their child's BG levels higher at night.

In addition to nocturnal hypoglycemia, episodes of SH occurring at school or in other places where the child is supervised by adults with limited knowledge about hypoglycemia or its treatment is a significant concern for parents. A study found that while the most common fear reported by parents concerning hypoglycemia was the occurrence of nocturnal episodes, the next most common fear was the child experiencing hypoglycemia when away from the parent [24]. Research on parental perspectives regarding their children's diabetes management at school is sparse but suggests that the majority of parents perceive it to be inadequate, as school personnel are often not formally trained in diabetes management [25]. School personnel have also reported concerns about liability, which prevents them from providing adequate routine care and emergency treatment, such as administering glucagon injections in cases of SH [26].

In addition to the factors mentioned previously, detection of pediatric hypoglycemia presents unique challenges. Usually, parents have to rely on their children to recognize and accurately label hypoglycemic symptoms and then report these to them in a timely manner. The only other methods of monitoring children for hypoglycemia is for parents to check BG levels frequently, be on the alert for visible signs and symptoms of low BG (e.g., flushed face, trembling and behavioral changes) and, if the child uses a CGM device, to monitor this device closely. Unfortunately, research indicates that both

youth and their parents often fail to recognize the early signs of hypoglycemia. A field study found that parents failed to detect hypoglycemia more than half of the time when their children's BG levels were <55 mg/dl (3.0 mmol/l) [27]. That same study found that children aged 6–11 years failed to detect more than 40% of their own low BG levels. A 6-month follow-up demonstrated that children who experienced subsequent SH were significantly poorer at hypoglycemia detection than those who did not experience any episodes.

Fear of hypoglycemia in Type 1 diabetes

Given the aversive nature of hypoglycemic episodes and the associated risk for harm, individuals with Type 1 diabetes can develop a significant FoH that can negatively impact quality of life, emotional wellbeing, diabetes management and glycemic control [28–30]. While some degree of fear is considered appropriate and adaptive given the potential danger of hypoglycemia, for some individuals it may become more extreme and problematic. For these individuals, FoH may result in increased anxiety about diabetes management, obsessive self-monitoring, deliberately keeping BG levels too high, dependence on others, feelings of guilt and frustration, a sense of loss of control, embarrassment, relationship stress and avoidant behavior [31].

To quantify FoH in adults with Type 1 diabetes, the HFS developed in 1987, continues to be the most commonly used instrument [28,32]. The HFS measures several facets of fear related to hypoglycemia and its negative consequences, including behavioral reactions, precipitating events, the phenomenological experience of FoH, negative interpersonal consequences and physiological outcomes [33]. The instrument is comprized of two subscales: the Behavior subscale (HFS-B), which measures behaviors used to avoid hypoglycemia and its negative consequences and the Worry subscale (HFS-W), which measures different anxiety-provoking aspects of hypoglycemia. In adults, FoH as measured by the HFS-II, is closely related to history of SH and hypoglycemia risk, as well as reduced hypoglycemic awareness [34–36]. However, the level of FoH does not necessarily remain stable and can increase or decrease over time depending on a patient's actual or perceived risk. For example, FoH may increase after a particularly traumatic hypoglycemic episode and it can decrease following medical or behavioral interventions that decrease risk [37–43]. FoH is also related to trait anxiety in adults. Specifically, individuals with higher levels of trait anxiety, indicating a tendency to experience increased anxiety across a wide spectrum of situations, also tend to have higher FoH [44–46]. In terms of the impact of FoH on diabetes management and clinical outcome, studies have not produced consistent results, with some finding an association between higher levels of FoH and poorer diabetes control [25,34] and others not finding this relationship [46–50].

Assessment of fear of hypoglycemia in pediatric Type 1 diabetes

Fear of hypoglycemia is also a common occurrence for children and adolescents with Type 1 diabetes and their families [51–55]. The earliest studies investigating FoH in the pediatric population adapted the adult HFS for use with children and their parents [52,54,55]. The HFS for Parents (PHFS) and the HFS for Children (CHFS) have the same subscale structure as the adult version, comprised of both a behavior (B) subscale and a worry (W) subscale. The current version of the CHFS has ten items on the CHFS-B subscale (e.g., 'keep blood sugars a little high to be on the safe side') and 15 items on the CHFS-W subscale (e.g., 'getting in trouble at school because of something that happens when my sugar is low'). The PHFS has ten items on the PHFS-B subscale (e.g., 'avoid having my child being alone when his/her sugar is likely to be low') and 15 items on the PHFS-W subscale (e.g., 'child not having food, fruit or juice with him/her').

Adequate reliability for the PHFS has been reported by several studies, with internal consistency ranging from 0.72 to 0.76 for the PHFS-B and 0.88 to 0.91 for the PHFS-W [29,55]. In addition to the PHFS created by our research group, other researchers have independently modified the original HFS to assess parental actions to prevent hypoglycemia in their children, as well as their concerns about their children experiencing hypoglycemia [54]. A more recent study [56] modified the survey for assessment of FoH in parents of very young children with Type 1 diabetes, including toddlers (e.g., 'Feed my child as soon as I feel or see the first signs of a low blood sugar.'). These modified parent versions have retained good internal consistency and test–retest reliability and they have yielded scores that were comparable to other published data [54,56].

Compared with the parent and adult versions of the HFS, there is less research on the psychometric properties of the CHFS, but the available findings indicate adequate reliability. In a recent study of FoH in adolescents with Type 1 diabetes, Cronbach's αs for the CHFS demonstrated adequate internal consistency for the CHFS-Total score and the CHFS-W (0.86 and 0.91, respectively), with lower internal consistency for the CHFS-B (0.54) [29]. In another independent modification of the adult HFS for a study of FoH in Type 1 children attending diabetes camp [52], the scale showed adequate internal consistency (Cronbach's α coefficients 0.85, 0.64 and 0.88 for the CHFS-Total, CHFS-B and CHFS-W, respectively) and test–retest reliability.

Early studies using the PHFS found higher levels of FoH in mothers whose children experienced loss of consciousness owing to hypoglycemia, as well as those who were highly distressed by their children's episodes during the night or in social situations [55]. There is also some evidence showing that maternal FoH is higher for those with children on multiple daily injections compared with an insulin pump [49,57,58]. In a study of mothers of younger children (2–8 year olds), maternal FoH did not correlate with child frequency of SH episodes, although this may have been attributable to an overall low rate of SH in the sample [56]. However, a study of mothers of adolescents with Type 1 diabetes also found no relationship between frequency of SH in their children and FoH. Instead, the only predictor was mothers' belief about whether or not their adolescent always carried fast-acting carbohydrate for hypoglycemic treatment [29]. A total of two studies have investigated correlates of FoH in adolescents with Type 1 diabetes, both finding that, like adults, frequency of SH predicted FoH [29,54]. Also similar to findings in adults, FoH in adolescents was associated with trait anxiety [29]. No published studies have yet investigated predictors of FoH in younger children.

Only one previous study has compared levels of FoH in mothers of younger children and those of older children and found no significant differences in level of FoH [56]. However, maternal FoH does appear to be significantly higher than paternal FoH, although it remains to be seen if this difference is clinically as well as statistically different [56,58]. Perhaps not surprisingly, more than one study has found that levels of FoH in mothers of youths with Type 1 diabetes are significantly higher than the levels observed in adult patient populations [55,56].

As in adults with Type 1 diabetes, there is an assumption that extreme FoH in either the parent or child can interfere with optimal diabetes management and control. That is, families with very high FoH may engage in more diabetes management behaviors to avoid hypoglycemia, which may lead to more frequent hyperglycemia. However, studies have, again, yielded inconsistent results. Several studies have investigated the relationship between FoH and diabetes control, based on the assumption that, if more FoH leads to more frequent hyperglycemia, HbA1c levels should be higher. Although some studies have not found an association between maternal or youth FoH and HbA1c levels [29,54,56,59], others have reported a positive correlation between mothers' FoH and their children's glycemic control [55,58]. Patton *et al.* reported a correlation between higher PHFS-B subscale scores and youth's HbA1c levels in mothers of young children with Type 1 diabetes, suggesting that parents of children in poorer metabolic control more frequently engage in behaviors to prevent hypoglycemia [56].

Although the majority of studies have used the PHFS and CHFS to study FoH in the pediatric Type 1 diabetes population, other researchers have used alternative measures. In general, these studies have reported findings comparable to those yielded with the PHFS and CHFS. For example, Nordfeldt and Ludvigsson examined fear of SH in youth with Type 1 diabetes and their parents using a Visual Analogue Scale [60], finding the highest levels of fear in youths who had experienced SH with unconsciousness and lower levels in those who experienced SH without unconsciousness. Kamps *et al.* developed the Children's Hypoglycemia Index to measure FoH in pediatric populations [61]. Preliminary results indicated that the Children's Hypoglycemia Index is a valid and reliable measure of youth FoH and that it significantly correlated with other measures of anxiety and FoH, including an early version of the CHFS [52].

Assessing fear of hypoglycemia across different age ranges in children with Type 1 diabetes & their parents: recent findings

As the aforementioned studies demonstrate, many important questions about FoH in youth with Type 1 diabetes and their parents have

not yet been addressed by research. No studies have examined FoH across a broad range of age groups in youth, often because of the relatively small numbers of subjects and restricted age ranges of youth. These limitations have posed a barrier to investigating questions that require larger subject samples, such as questions about changes in FoH across developmental stages. To date, there is only one reported age comparison in the literature which found that FoH in mothers of very young children was not greater than that reported by parents of older preadolescent children in an earlier study, but this was in a restricted age range [56]. Another fundamental question that has not been scientifically addressed is whether or not FoH can be reliably assessed in younger children. That is, can young children give reliable self-reports of their own fears regarding hypoglycemia? Generally, the literature on assessment of health-related quality of life in children supports the conclusion that even children as young as 5 or 6 years old can give reliable and valid self-reports [62–64]. However, no studies have yet investigated the reliability of FoH assessment across different youth age groups and established that younger children's responses to the CHFS are reliable and valid.

We have recently attempted to address these questions by aggregating CHFS and PHFS data from several separate studies conducted in our laboratory over the past decade. In addition to CHFS and PHFS data, each of these studies also included demographic (age of youth and gender) and clinical (HbA1c level and duration of diabetes) data, as well as other psychological measures relevant to HFS validity (e.g., anxiety measures, which are described in detail later). The total aggregated sample included 259 youths with Type 1 diabetes and 250 parents. Youths had a diagnosis of Type 1 for at least 1 year (mean: 5.24; standard deviation [SD]: 3.28 years) and ranged in age from 6 to 18 years (mean: 10.56; SD: 3.31 years). Youths (45.5% female) were divided into three age groups as follows: 6–8 years old (n = 85), 9–11 years old (n = 95) and 12–18 years old (n = 79). Over a third of the youths used insulin pump therapy (38%) and average HbA1c was 8.01% (0.97). For the parent sample, the majority were mothers (81.3%) and Caucasian (88%) and generally highly educated (mean education: 15.15; SD: 2.77 years).

■ Hypoglycemia Fear Survey for children & parents

Reliability

The first question addressed with this aggregated dataset was whether FoH can be reliably assessed by self-reported responses on the CHFS in younger children. Across all age groups, the CHFS showed adequate internal consistency (Cronbach's αs for CHFS-B = 0.70; CHFS-W = 0.89; and CHFS-Total = 0.85). To determine whether internal consistency was lower in younger children, Cronbach's αs were compared across age groups, which generally indicated adequate reliability for all three age ranges, although the coefficient for the CHFS-B (α = 0.59) in 12–18 year olds was slightly lower than expected. **Table 1** shows the reliability coefficients for each age group. Independent samples Feldt tests comparing reliability across age groups found no significant differences,

Table 1. Cronbach's αs for children's hypoglycemia fear survey and parent's hypoglycemia fear survey scores by age group.

		Child age (years)		
		6–8	**9–11**	**12–18**
CHFS	n	56	51	62
	CHFS-B	0.71	0.78	0.59
	CHFS-W	0.89	0.87	0.89
	CHFS-Total	0.84	0.87	0.84
PHFS	n	77	92	69
	PHFS-B	0.63	0.58	0.69
	PHFS-W	0.90	0.87	0.90
	PHFS-Total	0.88	0.84	0.87

CHFS: Children's hypoglycemia fear survey; CHFS-B Children's hypoglycemia fear survey behavior subset score; CHFS-Total: Children's hypoglycemia fear survey total score; CHFS-W: Children's hypoglycemia fear survey worry subset score; PHFS: Parent's hypoglycemia fear survey; PHFS-B: Parent's hypoglycemia fear survey behavior subset score; PHFS-Total: Parent's hypoglycemia fear survey total score; PHFS-W: Parent's hypoglycemia fear survey worry subset score.

indicating that self-reported CHFS responses are equally reliable in younger children and older youth.

The reliability of PHFS responses for parents of children in different age groups was also assessed. For the total parent sample across youth age groups, reliability of the PHFS was adequate (PHFS-B = 0.70, PHFS-W = 0.89, PHFS-Total = 0.86). **Table 1** shows Cronbach's αs for parents of youths in the three age groups and, again, independent samples' Feldt tests revealed no significant differences in PHFS reliability across youth age.

Validity

As evidence of construct validity, both CHFS and PHFS scores would be expected to correlate significantly with other measures of anxiety. CHFS-W subscale scores and CHFS-Total scores correlated significantly with State-Trait Anxiety Inventory for Children scores ($r = 0.41$, $p < 0.001$; $r = 0.36$, $p < 0.001$, respectively), while CHFS-B subscale scores did not. The State-Trait Anxiety Inventory for Children score has demonstrated reliability and validity in children as young as 8 years, but it can also be used in children as young as 6 years [101]. PHFS-W subscale scores and PHFS-Total scores also correlated significantly with trait anxiety scores from the adult State-Trait Personality Inventory ($r = 0.22$, $p < 0.01$; $r = 0.20$, $p < 0.01$, respectively), but PHFS-B subscale scores did not [65]. Although statistically significant, it should be highlighted that the magnitude of the relationship between trait anxiety and FoH was much lower for parents than for youths. As previously noted, at least one study has found that FoH in parents of adolescents with Type 1 diabetes did not relate to trait anxiety levels [29].

■ Hypoglycemia fear survey for childrens' & parents' scores across different age groups

This aggregated dataset was then used to examine possible differences in CHFS and PHFS scores across different youth age groups **(Table 2)**. For youths, only CHFS-W subscale scores differed across the age groups. *Post-hoc* comparisons showed that scores were higher in youths aged 9–11 years than in children aged 6–8 years ($p = 0.04$), but did not differ from scores in the older 12–18-year-old age group. For parents, PHFS-W scores were equivalent across the three age groups. However, PHFS-B scores were significantly higher for parents of children aged 6–8 years and 9–11 years ($p < 0.01$) compared with parents of 12–18-year-olds. These findings suggest that worries about hypoglycemia are relatively lower in younger-aged school children with Type 1 diabetes, but then increase to a plateau by the time children are approximately age 9 years or so. The child's age does not appear to affect parents' level of worry about hypoglycemia, but parents of younger children engage in significantly more behaviors to prevent hypoglycemia. Both of these findings seem developmentally- and age-appropriate given the changes in the division of responsibility for diabetes management between youths and their parents as children grow more cognitively and emotionally mature [66].

Table 2. Mean scores on hypoglycemia fear survey for children and hypoglycemia fear survey for parents across age groups.

		Child age (years)			ANOVA	
		6–8	9–11	12–18	df	F
		M (SD)	M (SD)	M (SD)		
CHFS	n	59	52	67		
	CHFS-B	2.18 (0.7)	2.21 (0.7)	2.11 (0.5)	(2, 106)	0.48
	CHFS-W	0.91 (0.7)	1.25 (0.8)	1.15 (0.7)	(2, 178)	3.24*
	CHFS-Total	1.41 (0.6)	1.63 (0.6)	1.53 (0.5)	(2, 175)	1.61
PHFS	n	77	92	69		
	PHFS-B	2.52 (0.6)	2.52 (0.5)	2.09 (0.7)	(2, 240)	14.56**
	PHFS-W	1.77 (0.7)	1.69 (0.6)	1.78 (0.6)	(2, 239)	0.41
	PHFS-Total	1.97 (0.6)	1.91 (0.5)	1.81 (0.6)	(2, 235)	1.44

*$p < 0.05$.
**$p < 0.001$.
CHFS: Children's hypoglycemia fear survey; CHFS-B Children's hypoglycemia fear survey behavior subset score; CHFS-Total: Children's hypoglycemia fear survey total score; CHFS-W: Children's hypoglycemia fear survey worry subset score; PHFS: Parent's hypoglycemia fear survey; PHFS-B: Parent's hypoglycemia fear survey behavior subset score; PHFS-Total: Parent's hypoglycemia fear survey total score; PHFS-W: Parent's hypoglycemia fear survey worry subset score.

■ Relationship between youth & parent hypoglycemia fear survey scores

A significant relationship between CHFS and PHFS scores might be expected for a variety of reasons, including similarities in youth–parent experiences with hypoglycemia. As expected, correlations between CHFS and PHFS scores, first across all age groups, were significant. However, the magnitude of these correlations was lower than expected (HFS-B: $r = 0.28$, $p < 0.001$; HFS-W: $r = 0.17$, $p < 0.05$) and HFS-Total ($r = 0.20$, $p < 0.05$). When correlations between CHFS and PHFS scores were computed separately for the three youth age groups, again only relatively weak relationships were observed and there was no correlation between parent and youth scores in the 6- to 8-year-old group **(Table 3)**.

Table 3. Correlations between parent's hypoglycemia fear survey and children's hypoglycemia fear survey scores across youth age categories.

	Age (years)		
	6–8	9–11	12–18
HFS-B	0.22	0.41*	0.29**
HFS-W	0.14	0.12	0.21
HFS-Total	0.19	0.29**	0.14

*p < 0.01.
**p < 0.05.
HFS-B: Hypoglycemia fear survey behavior subset score;
HFS-Total: Hypoglycemia fear survey total score;
HFS-W: Hypoglycemia fear survey worry subset score.

■ Relationship between fear of hypoglycemia & diabetes control

To assess the relationship between FoH and metabolic control, CHFS and PHFS scores were correlated with youth HbA1c measures. When correlations were computed separately for the three age groups, there were no significant relationships. However, when correlations were computed across all age groups, there was a significant relationship between PHFS-B subscale scores and HbA1c ($r = -0.15$, $p = 0.047$). This finding suggests that parents of youths with better diabetes control engaged in more behaviors to prevent hypoglycemia. This finding may reflect an association between more overall engagement in parental diabetes management behaviors and better control, or increased behaviors related to the increased risk for hypoglycemia when youths are in better control.

However, it is also the case that there is not necessarily a linear relationship between FoH and diabetes management or control [46]. For this reason, a final analysis compared youth HbA1c and BG readings in youths and parents who scored in the highest and lowest quartiles of CHFS and PHFS scores, indicating the highest and lowest levels of FoH. Youth scoring in the highest quartile had significantly more BG readings >300 mg/dl than those in the lowest quartile (4.7% compared with 3.0%, respectively, $F[1,73] = 6.18$, $p = 0.02$). They also had fewer BG readings in the target range of 70–180 mg/dl (44.1% compared with 50.3%, respectively, $F[1,73] = 5.76$, $p = 0.02$). However, for parents, higher PHFS scores were not associated with increased hyperglycemic BG readings in their children. Rather, parents with higher PHFS scores had children with lower mean HbA1c values than parents with lower PHFS scores (7.7% compared with 8.2%, respectively, $F[1,104] = 7.13$, $p = 0.01$).

■ Summary

These findings, using this larger aggregated dataset, show that children as young as 6–8 years old can provide reliable self-reports regarding their FoH using the CHFS. Children in this age group also report lower levels of FoH than children age 9 years and older, which is likely related to numerous developmental factors. These include young children's cognitive inability to fully comprehend and appreciate the potential serious consequences of hypoglycemia, as well as the child's reliance on the parent to be primarily responsible for managing low BG levels. By contrast, youth age had no impact on parental worry about hypoglycemia, which remained at a constant level across age groups. PHFS-B scores, however, did differ with youth age, with parents of children 6–11 years old engaging in significantly more behaviors to avoid hypoglycemia as compared with parents of adolescents, a tendency which seems developmentally appropriate.

One somewhat surprising result was the modest relationship observed between CHFS and PHFS scores across the age groups. This finding suggests that different factors may contribute to the development of FoH in youth and parents, a conclusion that is further supported by previous findings that different variables predicted levels of FoH in adolescents with Type 1 diabetes and their parents [29]. Other studies have also failed to find a relationship between parental FoH and youth's hypoglycemia history [24,29,55]. It may be that the qualitative characteristics of hypoglycemia experiences (e.g., the level of associated distress and trauma) may have more influence than the quantitative frequency of episodes in the development of parental FoH. In terms of the impact of FoH on glycemic control in pediatric diabetes, these results support the conclusion that this relationship is complex and not strictly linear. Parents with the highest levels of FoH had children in better control, this may be appropriate since these children are indeed at higher risk for hypoglycemia. By contrast, children with higher FoH had more high BG readings (>300 mg/dl), but not higher HbA1c levels than children with lower FoH.

Conclusion

This article has summarized the existing research on FoH and its assessment in families living with pediatric Type 1 diabetes and presented new evidence that the CHFS and PHFS can assess FoH in this population with

a reasonable degree of reliability and validity. In fact, it appears that children as young as 6 or 7 years of age can provide reliable self-reports regarding FoH. A version of the PHFS designed specifically for parents of very young children (i.e., under 8 years of age) with Type 1 diabetes has also been developed and the early results indicate that it, too, is reliable. From a research perspective, these instruments can provide a useful tool for assessing the impact of interventions designed to reduce the occurrence and negative impact of hypoglycemia, including newly developed treatments and technologies. From a clinical perspective, they can provide a tool for monitoring FoH and identifying those families who may need additional support, education or assistance in dealing with hypoglycemia.

In spite of the potential scientific and clinical utility of the PHFS and CHFS, more research is needed to increase our understanding of both the construct of FoH in pediatric diabetes and its impact on disease management and outcome. The new findings presented in this article, based on a large aggregated dataset, highlight the importance of investigating FoH across age ranges and developmental stages of youth with Type 1 diabetes and their parents. Large datasets are also needed for factor analysis studies, which can help to clarify the underlying domains of FoH that are measured by the PHFS and CHFS. Most previous studies in this area, with only a few exceptions [56,58], have focused on maternal FoH and we know little about paternal FoH. Perhaps most importantly, large datasets are needed to establish normative levels of FoH. Given the potential danger of hypoglycemia, some level of fear is adaptive and appropriate. Therefore, it is important to identify CHFS and PHFS scores reflecting a healthy level of concern, as well as those that indicate possible problematic levels of FoH.

The construct of FoH in pediatric patients and their parents has received relatively limited scientific attention over the past decade, which is somewhat surprising given its potential clinical significance and the apparent increase in Type 1 diagnosis in younger children in many parts of the world [67,68]. A recent review of the literature on FoH in parents of children under 12 years of age found only eight published studies that met their liberal criteria for inclusion [69]. That review and the present one, demonstrate that the majority of published studies have significant methodological limitations including: cross-sectional designs, solely descriptive analyses, limited sample sizes, narrow youth age ranges and a lack of outcome measures critical for testing hypotheses regarding the impact of FoH on diabetes management and outcome. More sophisticated research is needed, particularly longitudinal studies to follow families over time as they confront and are affected by hypoglycemia-related experiences. Such an approach would help shed light on factors influencing the development of FoH, as well as the impact of FoH on diabetes treatment and control. Like other types of stimulus -specific anxiety, FoH can suddenly increase with exposure to highly aversive and threatening experiences with hypoglycemia. However, it is still unclear exactly what characteristics of a hypoglycemia episode are most likely to lead to increased FoH. However, studies have found higher levels of FoH in parents with a history of the child passing out or having a seizure due to hypoglycemia and other types of distressing events. This suggests that families who have recently experienced a traumatic hypoglycemic episode may be most vulnerable to increased FoH and should be assessed for reactions that may interfere with quality of life or optimal diabetes treatment. FoH should also be assessed in families characterized by high levels of trait anxiety, even though the relationship between this personality trait and FoH in parents and younger children remains unclear. These families may need assessment even if they have not yet experienced traumatic hypoglycemic episodes since individuals very high in trait anxiety are predisposed to anticipatory anxiety, or anxiety about an event even before it actually occurs.

Research also needs to adopt more rigorous and comprehensive approaches to address the question of how FoH affects diabetes management and glycemic control. Studies attempting to address this question have examined the relationship between FoH and HbA1c, with two studies also using children's average daily BG meter readings [24,56]. To date, no studies have included measures, objective or subjective, of specific diabetes treatment behaviors that might be affected by FoH, such as frequency of checking BG levels or administering insulin boluses. Findings are inconsistent across studies and suggest that the relationship between

FoH and diabetes control is not linear, but rather quite complex. In some parents, high FoH may lead to more hypoglycemia avoidant behaviors and high BG levels while, in others, high FoH may be appropriately related to a child's elevated hypoglycemia risk secondary to tight diabetes control. Longitudinal studies are needed to follow families over significant time periods with prospective measures of hypoglycemia exposure, level of FoH, diabetes management behaviors and glycemic outcome variables.

Future perspective

In spite of the prevalence and negative impact of FoH in pediatric Type 1 diabetes, there has been virtually no research into interventions aimed to reduce FoH in this population. In adults, several interventions that decrease the risk for SH have been shown to also reduce FoH. These interventions range from behavioral to pharmaceutical to surgical and include Blood Glucose Awareness Training, treatment with insulin analoges and islet cell transplantation [38–43]. While it might be expected that a similar reduction in FoH would occur with use of CGM devices with alarms to warn of impending hypoglycemia, research findings have been mixed [70–72]. However, these studies have not yet focused directly on the impact of CGM on families with a history of frequent or severe episodes, or high levels of FoH. Research investigating the impact of other emerging technologies that may lower hypoglycemic risk, including closed loop glucose control systems, will likely grow in the future.

A noteworthy study testing an intervention to reduce SH in youth provides intriguing evidence that positive outcomes do not necessarily require highly complex programs or technology [60]. This study tested the widespread distribution of educational and training materials, including videotapes, aimed at teaching families appropriate and effective strategies for preventing hypoglycemia. The rate of SH in these families was subsequently cut almost in half and this reduction was maintained over several years. These results suggest that we may be missing opportunities to develop and implement interventions that are effective from an outcome and cost perspective at reducing the problem of hypoglycemia and its negative consequences, including FoH. In addition to interventions to reduce hypoglycemia risk, there is also a need for interventions that directly target extreme and problematic FoH, which may arise independent of actual hypoglycemia risk or history.

Looking into the future, another area of emerging importance will be FoH in pediatric Type 2 diabetes. Currently youth with Type 2 diabetes are typically managed with oral antihyperglycemic medications and the most pressing clinical concern is reducing chronic hyperglycemia. However, it is likely that over time it will become more common to use insulin regimens in this population in order to improve diabetes control. As this occurs, the problem of hypoglycemia and FoH will no doubt also increase.

Finally, an important area for future development will be the investigation of FoH as a global problem in pediatric Type 1 diabetes. There is a larger body of literature on FoH in adults with both Type 1 and Type 2 diabetes across other countries, including Germany, The Netherlands, Slovenia, the UK, China, Sweden and Turkey [73–78]. In pediatric diabetes, there is some encouraging growth in cross-cultural studies. For example, results from a recent Norwegian population-based study demonstrated that parental FoH was prevalent and was related to both increased emotional distress in parents and poorer glycemic control in children [58]. Other ongoing research projects are looking at FoH in youth with Type 1 diabetes and their parents in additional countries, including Turkey, Iran, Germany and the UK, and findings from these studies will soon be added to our knowledge base. This research will further advance our understanding of the global relevance of FoH and provide the opportunity to identify similarities and differences across countries and cultures.

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