Understanding the Construct of Fear of Hypoglycemia in Pediatric Type 1 Diabetes

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Objective Fear of hypoglycemia (FoH) can be a significant barrier to glycemic control in pediatric type 1 diabetes (T1D). This study aimed to explore underlying constructs of the Hypoglycemia Fear Survey (HFS) for parents (PHFS) and children (CHFS).

Methods Data were aggregated from five studies of 259 youth with T1D and 250 parents. Exploratory Factor Analysis was used to determine the underlying factors of the CHFS and PHFS.

Results Similar four-factor solutions were found for the CHFS and PHFS. Both subscales consisted of two factors: Behavior Subscale (1) behaviors used to keep blood glucose (BG) high to prevent hypoglycemia (Maintain High BG) and (2) other actions to avoid hypoglycemia (Avoidance); Worry Subscale (1) concerns about helplessness (Helplessness) and (2) negative social consequences associated with hypoglycemia (Social Consequences).

Conclusions These constructs provide a more comprehensive understanding of pediatric FoH and have implications for interventions aimed at reducing FoH in this population.

Key words: anxiety; diabetes; quality of life.

Hypoglycemia is one of the most dangerous consequences of insulin therapy for children and adolescents with T1D, and a primary barrier to optimal glucose control (Cryer, 2012). Episodes of severe hypoglycemia (SH) can be associated with mental disorientation, loss of consciousness, and even seizures, making SH especially frightening to children and their parents (Clarke, Jones, Rewers, Dunger, & Klingensmith, 2009). Youth who maintain tight glycemic control are at increased risk for both moderate and SH episodes, presenting a significant dilemma for families attempting to achieve optimal diabetes management (Lehecka, Renukuntla, & Heptulla, 2012).

Given the frequent occurrence of hypoglycemia and its potential life-threatening consequences, it is no surprise that fear of hypoglycemia (FoH) is common for children with T1D and their parents (Barnard, Thomas, Royle, Noyes, & Waugh, 2010; Clarke, Gonder-Frederick, Snyder, & Cox, 1998; Green, Wysocki, & Reineck, 1990; Gonder-Frederick, Clarke, & Cox, 1997; Marrero, Guare, Vandagriff, & Fineberg, 1997; Gonder-Frederick, Nyer, Shepard, Vajda, & Clarke, 2011). In fact, mothers of children with T1D have demonstrated higher levels of FoH than adults with T1D (Clarke et al., 1998; Patton, Dolan, Henry, & Powers, 2008). As parents manage the majority, if not all, of younger children’s diabetes care, FoH, especially during the night, can result in increased parenting stress, perceived parental burden, and more frequent nighttime awakenings to monitor blood glucose (BG) levels (Haugstvedt, Wentzel-Larsen, Rokne, & Graue, 2011; Monaghan, Hilliard, Cogen, & Streisand, 2009; Patton, Dolan, Henry, & Powers, 2007; Streisand, Swift, Wickmark, Chen, & Holmes, 2005). Given the real danger associated with hypoglycemia, some FoH is to be expected, and even adaptive. Adaptive levels of fear are...
likely associated with appropriate hypoglycemia prevention behaviors, such as more frequent BG monitoring. However, extremely high levels of FoH may lead to the child or parent over-treating initial signs of low BG and contribute to a pattern of management that promotes high BG, with the potential to have a negative impact on glycemic control (Clarke et al., 1998). Higher levels of FoH can also have a negative impact on quality of life and increase perceived diabetes burden in both children with T1D and their parents (Barnard et al., 2010; Johnson, Cooper, Davis, & Jones, 2013).

Not surprisingly, parental FoH has been shown to be related to hypoglycemia history, including previous episodes resulting in seizure or loss of consciousness, as well as frequency of episodes (Clarke et al., 1998; Gonder-Frederick, Nyer, et al., 2011; Marrero et al., 1997; Monaghan et al., 2009; Patton et al., 2007, 2008). Personality constructs may also be associated with FoH, with higher levels of FoH found in mothers showing higher levels of trait anxiety, a relationship also found in adults with T1D (Gonder-Frederick, Nyer, et al., 2011; Polonsky, Davis, Jacobson, & Anderson, 1992). In mothers of adolescents, FoH has been shown to be related to maternal beliefs regarding whether their teenager carried fast-acting carbohydrates for hypoglycemia treatment (Gonder-Frederick et al., 2006). In addition, parental FoH can be related to type of insulin regimen, with higher FoH for mothers with children on multiple daily injections (MDI) compared with those with children on insulin pump therapy (Haugstvedt, Wentzel-Larsen, Graue, Søvik, & Rokne, 2010; Muller-Godeffroy, Treichel, Wagner, & German Working Group for Paediatric Pump Therapy, 2009; Nixon & Pickup, 2011). In children and adolescents with T1D, trait anxiety appears also to be associated with FoH (Gonder-Frederick et al., 2006; Gonder-Frederick, Nyer, et al., 2011). However, the relationship between pediatric FoH and previous episodes of hypoglycemia is unclear with research yielding mixed results (Gonder-Frederick et al., 2006; Johnson et al., 2013; Marrero et al., 1997).

The most widely used instruments for quantifying FoH in pediatric diabetes are adaptations of the original Hypoglycemia Fear Survey (HFS) developed for adults (Cox, Irvine, Gonder-Frederick, Nowacek, & Butterfield, 1987), including separate versions for children (CHFS) and parents (PHFS) (Barnard et al., 2010; Gonder-Frederick, Nyer, et al., 2011). The CHFS and PHFS are composed of two subscales—a Behavior Subscale that measures different types of behaviors to prevent hypoglycemic episodes and their negative consequences (e.g., Carry fast-acting carbohydrates) and a Worry Subscale that measures different types of concerns related to hypoglycemia and its negative consequences (e.g., No one being around to help during a low). Past research has demonstrated the reliability and validity of both the CHFS and the PHFS (Gonder-Frederick et al., 2006; Gonder-Frederick, Nyer, et al., 2011; Patton et al., 2008) and that children as young as 6 to 8 years of age are able to provide reliable self-reports, with alpha coefficients of 0.71, 0.89, and 0.84 for Behavior, Worry, and Total scores, respectively, compared with alphas of 0.78, 0.87, and 0.87 for 9–11-year-old and 0.59, 0.89, and 0.84 for 12–18-year-old youth (Gonder-Frederick, Nyer, et al., 2011).

In spite of their common usage and previous psychometric findings, the factor structures of the CHFS and PHFS have not yet been analyzed. These analyses are vital to gain a better understanding of the constructs underlying pediatric and parental FoH, as well as the impact of fear on diabetes management and outcome. Recent factor analysis of the adult HFS has validated a two-factor solution reflecting the Behavior and Worry subscales (Gonder-Frederick, Schmidt, et al., 2011) but also found that the Behavior subscale is better described by two separate factors reflecting (1) actions aimed at keeping BG levels higher and (2) other strategies to avoid hypoglycemia. A major barrier to previous factor analyses of the CHFS and PHFS has been the lack of pediatric studies with an adequately large sample size. The present study aimed to overcome this barrier by using an aggregated sample of youth with T1D and their parents who participated in studies conducted in our laboratory over the past decade.

The purpose of the current study was to conduct the first investigation of the underlying factor structure of the CHFS and PHFS using exploratory factor analysis (EFA). EFA was warranted because it could not be assumed that the pediatric and parent versions would have the same three-factor structure as the adult HFS (Gonder-Frederick et al., 2013; Gonder-Frederick, Schmidt, et al., 2011). Importantly, there are notable discrepancies between the adult and pediatric versions that preclude conducting confirmatory analysis, for example, differences in the number of items, with 33 and 25 items on the adult HFS and pediatric versions, respectively, as well as differences in item content. In addition to CHFS and PHFS responses, these data sets also included a number of demographic, medical, and psychological variables, including trait anxiety questionnaires, hypoglycemia history, BG readings, and HbA1c measures. This allowed us to investigate relationships between factors of the CHFS and PHFS and relevant demographic and clinical variables to assess the construct and concurrent validity of factors, and to explore possible
implications of FoH for diabetes management and medical outcome.

Methods
Participants and Procedures
Data were aggregated from five past studies conducted at our laboratory between 2002 and 2010, which included children and adolescents with T1D and their parents. All five projects received institutional review board approval, and informed consent and assent were obtained from parents and youth at the time of study participation. Participants were recruited through diabetes clinics, diabetes advocacy/support groups, and advertisements. For all studies, inclusion criteria were youth T1D diagnosis for > 1 year and willingness of the parent/child to obtain at least 4 BG readings/day over a 4-week period (in four out of the five studies). This criterion was included to ensure collecting an adequate sample size of BG readings for analysis. The parent participating in the study was required to be the one primarily responsible for most of the child’s diabetes care. Exclusionary criteria included medical comorbidities that could affect children’s glycemic control, hypoglycemia, or hypoglycemic awareness (e.g., asthma controlled with inhalers, cystic fibrosis), as well as cognitive or learning disabilities in children or parents, making them unable to complete questionnaires. The only differences in inclusion/exclusion criteria across the studies were age requirements for the child. Most of the children/adolescents participating received their diabetes care at an Endocrinology Clinic in an academic medical center. All data, including questionnaires, BG meter data, and Hba1c levels, were obtained during study orientation meetings and baseline assessments, which took place in research centers. The one exception to this protocol was a study of adolescents and parents that required completion of questionnaires while in clinic waiting areas (Gonder-Frederick et al., 2006).

The aggregated sample included 259 youth with T1D and 250 parents. Youth (52% male, 48% female) had an average diagnosis duration of 5.24 ± 3.28 years and ranged in age from 6 to 18 years (10.56 ± 3.31 years). Average Hba1c was 8.01% (0.97). Parents included mostly mothers (88%) and a small number of fathers (12%). Parent ethnicity was primarily Caucasian (93%), with a small number of African-American (4%), Hispanic (2%), and Asian or Pacific Islander (1%) participants. The majority of parents were married (87%) and the minority were widowed (2%), living with a partner (0.4%), separated/divorced (9%), or never married (2%). Parents were generally highly educated (15.15 ± 2.77 years). MDI versus continuous subcutaneous insulin infusion (CSII) were used by 60% and 40% of the children, respectively. Most of the children (92%) did not have any reported long-term diabetes complications, and most parents (84%) reported that their children did not experience hypoglycemia unawareness.

Demographic, Hypoglycemia History, and BG Measures
During each study’s baseline visit, parents completed a questionnaire assessing demographic and clinical information, including hypoglycemic history. Items regarding hypoglycemic history covered a 1-year period and included the number of (1) episodes of SH; (2) hospital admissions due to hypoglycemia; (3) emergency room treatments (without hospital admission) for hypoglycemia; (4) rescue/Emergency Medical Technician (EMT) treatments for hypoglycemia (not taken to hospital). Items 2, 3, and 4 were compiled into a measure of the total number of hypoglycemic incidents resulting in medical attention. Number of episodes of SH was analyzed as a separate variable. All studies also included a laboratory assessment of Hba1c levels, and all but one study included BG meter data for children (N for this subset = 211), consisting of approximately 100 total readings obtained over a 1-month period. The total number of BG readings obtained was 22,567 with an average of 106.9 readings per child (SD = 6.7). These data were used to compute several glycemnic profile variables for youth including mean BG and percent of readings in hypoglycemic, euglycemic, and hyperglycemic ranges. Mean number of readings in each range was <70 mg/dl = 8.53% (6.62), 70–180 mg/dl = 44.65 (121.54), and >180 mg/dl = 46.41 (14.14).

FoH Measures
The CHFS and PHFS are 25-item self- and parent-report measures of pediatric FoH (Gonder-Frederick et al., 2006; Gonder-Frederick, Nyer, et al., 2011). Items are rated on a 5-point Likert scale (0 = ‘never’ to 4 = ‘almost always’). For both measures, individual Behavior Subscale and Worry Subscale scores can be obtained (sum of items), as well as a Total score for the subscales. Cronbach’s alphas for the CHFS range from 0.59 to 0.78, 0.87 to 0.89, and 0.84 to 0.87 for the Behavior Subscale, Worry Subscale, and Total Scores, respectively (Gonder-Frederick, Nyer, et al., 2011). For the PHFS, Cronbach’s alphas range from 0.72 to 0.76, 0.88 to 0.91, and 0.89 to 0.92 for the Behavior, Worry, and Total Scores, respectively (Gonder-Frederick, Nyer, et al., 2011), and a version of the survey designed for parents of very young children has demonstrated adequate test-retest reliability (Patton et al., 2008).
**Anxiety and Depression Measures**

The 10-item Trait Anxiety Subscale and the 10-item Trait Depression Subscale from the revised State-Trait Personality Inventory (STPI; Spielberger et al., 1979) were used to measure trait anxiety and depressive symptoms in parents. The STPI has demonstrated good internal consistency, with alpha coefficients ranging from 0.80 to 0.87 (Spielberger et al., 1979), as well as construct validity (Ritterband & Spielberger, 1996).

The State-Trait Anxiety Inventory for Children, Trait Subscale (STAIC), was used to measure trait anxiety in youth (Spielberger & Edwards, 1973). Although initially designed for use with children 9–12 years of age, research has found the STAIC reliable for children as young as 6 years (Cabrera, Urrutia, Vera, Alvarado, & Vera-Villarroel, 2005; Hodges, 1990).

**Data Analysis**

EFA was conducted using Mplus (Muthén & Muthén, 2009) to assess the dimensional structure of the surveys. All items were allowed to load on any factor. Multiple models (2-factor, 3-factor, 4-factor) were tested; however, only the strongest factor solutions are presented here. Model fit was estimated using a chi-square goodness of fit statistic, root mean square error of approximation (RMSEA), standardized root mean square residuals (SRMR), Comparative Fit Index (CFI), and the Tucker-Lewis Index (TLI). Although there is debate about cutoffs for fit indices (Marsh, Hau, & Wen, 2004), in general, RMSEA and SRMR values <0.10 indicate acceptable fit (Hu & Bentler, 1998) and CFI and TLI values >0.90 indicate acceptable fit (Bentler & Bonett, 1980).

Following factor structure analyses, each factor was examined for potential group differences, relationships with clinical variables, and concurrent validity with the parent and children’s trait anxiety/depression scores. Pearson correlations were used to assess for associations between factor scores and clinical variables, and analyses of variance were used to investigate group differences as well as to further examine subscale scores’ relations to glycemic control variables (BG readings and HbA1c measures).

**Results**

**Factor Analysis**

EFA analyses revealed a poor fit for the one-, two-, and three-factor models, with RMSEAs > 0.10, CFIs < 0.90, and TLIas < 0.90. Four-factor solutions, described in detail below, appeared to be the best fit for both the CHFS and PHFS.

**CHFS**

The four-factor solution for the CHFS, presented in Table I, showed the best fit both statistically and conceptually: $\chi^2_{(63)} = 128.1$ ($p < .00005$), RMSEA = 0.08, SRMR = 0.06, CFI = 0.93, and TLI = 0.95. All items loaded significantly (>0.30) onto one of the four factors. The Behavior Subscale split into two factors: (1) “Maintain High BG” representing actions to maintain high BG to prevent hypoglycemia (e.g., Keep blood sugars a little high to be on the safe side), and (2) “Avoidance” including other actions aimed at avoiding hypoglycemia and its negative consequences (e.g., Avoid being alone when BG could drop). Loadings ranged from 0.66 to 0.81 for the Maintain High BG factor and 0.31 to 0.67 for the Avoidance factor, respectively. The only Behavior Subscale item not loading onto either of these two factors was CHFS-B1, Eat large snacks at bedtime, which loaded onto a factor otherwise composed of Worry Subscale items (see Table I for factor loadings and Cronbach’s alphas).

The CHFS Worry Subscale also split into two factors: (1) “Helplessness,” which included 10 items reflecting concerns about being alone and/or helpless during a hypoglycemic episode (e.g., No one being around to help me), and (2) “Social Consequences,” which included the remaining six Worry Subscale items representing concerns about possible negative social consequences due to hypoglycemia (e.g., Looking ‘stupid’ or clumsy). Loadings ranged from 0.38 to 0.84 and 0.36 to 0.95, for Helplessness and Social Consequences, respectively.

**PHFS**

A similar four-factor solution (see Table I) fit the PHFS, with two Behavior Subscale factors (Maintain High BG and Avoidance) and two Worry Subscale factors (Helplessness and Social Consequences). Fit statistics for the PHFS factor structure were $\chi^2_{(73)} = 155.8$ ($p < .00005$), RMSEA = 0.07, SRMR = 0.05, CFI = 0.95, and TLI = 0.97, with all items loading onto one of the four factors (>0.30). Items on the Behavior Subscale split onto two factors mirroring the CHFS-B factors, with loadings ranging from 0.38 to 0.92 for the Maintain High BG factor and 0.40 to 0.68 for the Avoidance factor. The Worry Subscale also split across two factors similar to those found for the CHFS, with loadings on the Helplessness factor ranging from 0.38 to 0.79 and loadings on the Social Consequences factor ranging from 0.54 to 0.87. PHFS and CHFS items loading onto the four factors were generally consistent, with the exception of four of the 25 items loading onto different factors.
Internal Reliability of CHFS and PHFS Factors

As shown in Table I, Cronbach alphas for the CHFS and PHFS ranged from 0.77 to 0.89 for the Maintain High BG, Helplessness, and Social Consequences factors, but were lower for the Avoidance factors with coefficients of 0.64 and 0.60 for children and parents, respectively. Cronbach alphas were also computed for the three different age groups for children/adolescents. For the 6–8, 9–11, and 12–18-year-old groups, respectively, alpha coefficients were 0.68, 0.83, and 0.80 for the Maintain High BG factor, and 0.69, 0.72 and 0.46 for the Avoidance factor. Coefficients for the age groups were 0.85, 0.87, and 0.84 for the Helplessness factor and 0.77, 0.79, and 0.80 for the Social Consequences factor.

Demographic Variables and CHFS/PHFS Factor Scores

One-way analyses of variance were used to investigate group differences in CHFS and PHFS factor scores across gender and age. Girls (M = 1.33, SD = 0.93) scored higher than boys (M = 1.08, SD = 0.65) on the CHFS Helplessness factor (F = 4.33, p = .039), with no other gender differences. No differences in any factor score were found between those on CSII (Ns range from 78 to 92) and MDI (Ns range from 76 to 140), Fs = 0.007–2.755, p’s = .099–.934. Youth age was categorized into three groups: 6–8 (N = 85), 9–11 (N = 95), and 12–18-year-olds (N = 79). No age differences were found in CHFS factor scores; however, child age was positively associated with higher CHFS scores on the Social Consequences factor (r = 0.17, p = 0.026), indicating increasing concern about the negative social effects of hypoglycemia in older children.

Both PHFS Behavior factors showed significant differences based on the youth age group. Parents of older children (12–18 years) scored lower (M = 1.27 ± 0.86) than both groups of parents of younger children on the Maintain High BG factor (M = 1.76 ± 0.78, M = 2.02 ± 0.86;
F = 16.08, p < .0005). Parents of children aged 12–18 years also scored significantly lower (M = 3.03 ± 0.56) on the Avoidance factor than parents of children aged 9–11 (M_{12–18} = 2.65 ± 0.74, F = 7.05, p = .001). No differences were found between youth age groups on PHFS Worry factor scores. There were no differences between parents of youth using CSII versus MDI.

**Validity**

The relationship between factor scores and relevant clinical variables, including hypoglycemia history, diabetes duration, and glycemic control, were examined to assess construct validity. There was a positive association between number of SH episodes in the past year and CHFS Helplessness factor scores (r = 0.19, p = .010). In addition, there was a positive association between CHFS Avoidance factor scores and duration of diabetes, r = 0.15, p = .039, and a negative association with the number of times medical attention was needed due to hypoglycemia, r = −0.17, p = .025. There were no other relationships between CHFS factors and SH variables. None of the PHFS factors related to history of SH or diabetes duration. There were no significant correlations between any factor scores and HbA1c.

To further examine differences in PHFS and CHFS factor scores across glycemic profile variables, factor scores were split into tertiles to compare those with the highest and lowest FoH scores. Glycemic profile variables included mean BG level, percent of readings in a euglycemic range, <70 mg/dl, and >180 mg/dl, number of SH episodes in the past year, and number of hypoglycemic episodes resulting in medical intervention. For the CHFS and PHFS Worry Subscale factors (Helplessness and Social Consequences), there were no glycemic differences between low and high tertile groups. In contrast, there were significant differences for the Behavior Subscale factors, which are shown in Table II. Children scoring in the highest tertile of the Maintain High BG factor had higher mean BG values (F_{1,84} = 5.09, p = .027), a greater percent of readings over 180 mg/dl (F_{1,84} = 5.37, p = .023) and 240 mg/dl (F_{1,84} = 5.40, p = .023), and more SH episodes (F_{1,111} = 5.22, p = .024) compared with those in the lowest tertile. For parents, there were no differences in children’s glycemic profile variables for those scoring in the highest and lowest tertiles of the Maintain High BG factor. Children in the highest tertiles of both the Avoidance and Maintain High BG factors had significantly fewer euglycemic readings than those in the lowest tertiles (F_{1,92} = 5.19, p = .023). For parents, the only difference found was that those scoring in the highest tertile of the Avoidance factor had children with significantly lower mean HbA1c values F_{1,108} = 6.21, p = .014.

To assess concurrent validity, correlations were computed between CHFS and PHFS factor scores and parent anxiety/depression and youth’s anxiety measures, respectively (see Table III). Higher scores on both Worry Subscale factors were associated with higher parent and child trait anxiety, as well as higher parent depression. There was no relationship between Behavior Subscale factors and youth or parent trait anxiety, or parent depression.

**Discussion**

Analysis of a large aggregated sample of CHFS and PHFS data yielded similar four-factor solutions for both children with T1D and their parents, with two Behavior Subscale factors (Maintain High BG and Avoidance) and two Worry Subscale factors (Helplessness and Social Consequences). Fit statistics for both the CHFS and PHFS models were good, with all items loading significantly (>0.30) onto one of the four factors for each measure. Overall, the same items loaded onto these factors for the CHFS and PHFS, with only 4 of 25 items showing differential loadings. This finding is not likely to be a methodological artifact because, in the studies included, parents and youth typically completed questionnaires in separate spaces in the presence of research team members who were available to answer any questions. Internal consistency was adequate for the two Worry Subscale factors and one of the Behavior Subscale factors (Maintain High BG) of the CHFS and the PHFS, indicating that items in these factors were generally homogenous and served as appropriate measures of the same construct. Internal consistency for the Avoidance factor of the Behavior Subscale was lower for both children and parents, which is likely due to the wide variety of item content (e.g., *always carry fast acting sugar vs. avoid child being alone when BG could drop*), making this factor less homogenous. Overall, the findings provide support for concurrent validity, with CHFS and PHFS Worry Subscale factors correlating positively with trait anxiety for children and parents, while Behavior Subscale factors were unrelated to anxiety. It should be noted, however, that no causal inferences can be made from these cross-sectional data regarding the direction of association between trait anxiety and FoH.

The factors identified for the Behavior Subscales of the CHFS and PHFS matched those found in adults with T1D, further supporting the validity of this structure. CHFS Behavior Subscale factors were also associated with several glycemic outcome variables but in different ways. For youth, increased Maintain High BG factor scores were associated with higher mean BG levels and more
hyperglycemic readings, but not with higher HbA1c. Although no causal connections between FoH and clinical outcome can be made based on these cross-sectional data, these findings suggest that more research, especially longitudinal, is needed to determine whether endorsing these items is indicative of a tendency to keep BG levels higher to reduce hypoglycemic risk, which may eventually have a negative impact on HbA1c. Children and adolescents who had experienced more frequent SH also showed higher scores on the Maintain High BG factor, also suggesting that longitudinal studies are needed to understand the complex relationships between hypoglycemia history, diabetes management, and FoH.

Youth with higher scores on the Avoidance and Maintain High BG factors had significantly fewer BG readings in a euglycemic range, another indicator of diabetes control. However, higher CHFS Avoidance scores were also associated with a lower incidence of hypoglycemic episodes requiring medical attention, a positive glycemic outcome. Somewhat surprisingly, PHFS scores on the Maintain High BG factor were not associated with any of their children’s glycemic profile variables, which is in contrast to other studies finding a relationship between higher parental FoH and poorer diabetes control in children with T1D (Haugstvedt et al., 2010; Patton et al., 2008). In this study, higher PHFS Avoidance scores were found for parents whose children had lower HbA1c measures, who may have more hypoglycemic episodes and benefit from more behaviors aimed at decreasing this risk. However, these associations between HFS scores and markers of glycemic control should be interpreted with caution given the inclusion requirement that parents and children be willing to obtain four or more BG readings per day over a 4-week period. Families willing to invest more time and effort into diabetes management behaviors such as BG monitoring may also exhibit better glucose profiles and control.

The CHFS and PHFS Worry Subscales yielded two factors reflecting concerns about the child being alone or without adequate help during hypoglycemia (Helplessness) and the child experiencing negative social consequences due to hypoglycemia (Social Consequences). Factor analysis studies of adults with T1D in the United States have repeatedly yielded only one factor for the Worry Subscale (Gonder-Frederick et al., 2013; Gonder-Frederick, Table II. Glycemic Profile Variables Means (SD) for Those in the Lowest and Highest Tertiles of CHFS and PHFS Behavior Subscale Factors

<table>
<thead>
<tr>
<th>Glycemic profile variable</th>
<th>CHFS MH BG</th>
<th>Avoid</th>
<th>PHFS MH BG</th>
<th>Avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean BG (mg/dl)</td>
<td>177.89*</td>
<td>192.07</td>
<td>177.91</td>
<td>184.49</td>
</tr>
<tr>
<td></td>
<td>(23.06)</td>
<td>(32.03)</td>
<td>(29.39)</td>
<td>(24.27)</td>
</tr>
<tr>
<td>Mean HbA1c (%)</td>
<td>8.32</td>
<td>7.98</td>
<td>8.72</td>
<td>8.01</td>
</tr>
<tr>
<td></td>
<td>(1.08)</td>
<td>(0.68)</td>
<td>(1.03)</td>
<td>(0.75)</td>
</tr>
<tr>
<td>% of readings &lt; 70</td>
<td>6.28</td>
<td>6.20</td>
<td>7.17</td>
<td>7.70</td>
</tr>
<tr>
<td></td>
<td>(5.41)</td>
<td>(6.37)</td>
<td>(5.97)</td>
<td>(6.64)</td>
</tr>
<tr>
<td>% of readings 70–180</td>
<td>49.62*</td>
<td>44.29</td>
<td>49.52*</td>
<td>44.90</td>
</tr>
<tr>
<td></td>
<td>(11.07)</td>
<td>(11.19)</td>
<td>(11.42)</td>
<td>(9.22)</td>
</tr>
<tr>
<td>% of readings &gt; 180</td>
<td>43.19*</td>
<td>48.39</td>
<td>42.80</td>
<td>46.29</td>
</tr>
<tr>
<td></td>
<td>(12.14)</td>
<td>(13.56)</td>
<td>(13.39)</td>
<td>(11.65)</td>
</tr>
<tr>
<td>Number of SH in past year</td>
<td>0.15*</td>
<td>0.58</td>
<td>0.27</td>
<td>0.63</td>
</tr>
<tr>
<td></td>
<td>(0.55)</td>
<td>(1.12)</td>
<td>(0.90)</td>
<td>(1.79)</td>
</tr>
<tr>
<td>Medical treatment for Hypo</td>
<td>0.11</td>
<td>0.15</td>
<td>0.13</td>
<td>0.12</td>
</tr>
<tr>
<td></td>
<td>(0.43)</td>
<td>(0.50)</td>
<td>(0.46)</td>
<td>(0.44)</td>
</tr>
</tbody>
</table>

Note. Asterisk (*) denote significant differences (p < .05) between the highest and lowest tertiles in each row (means and standard deviations of relevant tertiles are highlighted in bold).

Table III. PHFS and CHFS Factor Correlations With Parent Trait Anxiety and Depression and Child Trait Anxiety

<table>
<thead>
<tr>
<th>PHFS (CHFS) factor</th>
<th>Parent trait anxiety</th>
<th>Parent trait depression</th>
<th>Child trait anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHFS Maintain High BG</td>
<td>0.116</td>
<td>0.056</td>
<td>−0.096</td>
</tr>
<tr>
<td>PHFS Avoidance</td>
<td>−0.021</td>
<td>−0.043</td>
<td>−0.116</td>
</tr>
<tr>
<td>PHFS Helplessness</td>
<td>0.305**</td>
<td>0.252**</td>
<td>0.271**</td>
</tr>
<tr>
<td>PHFS Social Consequences</td>
<td>0.326**</td>
<td>0.271**</td>
<td>0.304**</td>
</tr>
<tr>
<td>CHFS Maintain High BG</td>
<td>0.029</td>
<td>0.028</td>
<td>0.117</td>
</tr>
<tr>
<td>CHFS Avoidance</td>
<td>0.068</td>
<td>0.07</td>
<td>0.029</td>
</tr>
<tr>
<td>CHFS Helplessness</td>
<td>0.163*</td>
<td>0.237**</td>
<td>0.326**</td>
</tr>
<tr>
<td>CHFS Social Consequences</td>
<td>0.235**</td>
<td>0.234**</td>
<td>0.416**</td>
</tr>
</tbody>
</table>

Note. *p < .05; **p < .01.
However, a Swedish study of adults with T1D found a similar factor reflecting concerns about having a hypoglycemic episode when no help was available, which the authors named the “Aloneness” factor (Anderbro et al., 2008). Given the potential danger of hypoglycemic episodes that occur when an individual is alone and unable to obtain needed treatment, these concerns are warranted, and it is unclear why this factor has not emerged in other adult studies. Children with higher scores on the Helplessness factor had more frequent past SH episodes, and further research is needed to investigate the implications of this relationship on diabetes management and quality of life. In contrast, higher PHFS scores on the Helplessness factor were not associated with SH frequency. The relationship between parental FoH and their child’s hypoglycemic history has yielded inconsistent results in previous studies, with only some finding higher FoH in parents whose children have suffered more severe or more frequent episodes (Clarke et al., 1998; Gonder-Frederick et al., 2006; Patton et al., 2008). The discrepant findings may be related to differences in how hypoglycemic variables are computed or other measurement issues across studies.

The Social Consequences factor on the CHFS and PHFS Worry Subscale, reflecting concerns about the child being criticized or evaluated negatively, has not been identified in previous FoH studies. However, there is evidence that that, in adolescent boys, FoH mediates the relationship between social anxiety and insulin adherence, suggesting that there is a complex relationship between social concerns and coping with the risk of hypoglycemia in this age group (Di Battista, Hart, Greco, & Gloizer, 2009). Our sample size did not permit computing separate factor analyses for different age groups; however, age correlated positively with scores on the Social Consequences factor indicating that, as children grow older, they become more concerned about and more aware of the potential negative social impact of hypoglycemia.

There are several methodological limitations of this study that need to be considered. Because this is the first examination of the factor structure of the CHFS and PHFS, these results require replication, especially in more diverse ethnic and racial groups who were poorly represented in our sample of primarily Caucasian, highly educated, and intact families. In addition, while we found no differences in factor scores across age groups, studies with larger sample sizes would allow a more in-depth investigation of age differences and developmental changes in FoH in youth. Our study also aggregated data collected over a 10-year period, which could be problematic given possible changes in diabetes management and hypoglycemia prevention over a decade, including more common use of long-acting basal insulins. However, a comparison of the average number of SH episodes reported in the early and more recent studies in our sample found no differences ($p = .536$). A final issue related to our sample is the average HbA1c in youth (8.1%), which is lower than estimates (8.6%) from the T1D Exchange Clinical Registry (Cengiz et al., 2013). Although this may indicate that pediatric patients in poorer control are underrepresented in our sample, similar mean HbA1c levels were reported by the SEARCH for Diabetes in Youth study (8.18%; Paris et al., 2009), as well as a recent Australian study of FoH in pediatric diabetes (8.0%; Johnson et al., 2013). Another possible limitation of the representativeness of our sample was the requirement that families be willing to perform BG monitoring four times per day during the study, which may have resulted in participants who are more engaged in their diabetes management and perhaps in better glycemic control. Finally, although this study found differences in clinical variables (mean BG levels, percent of BGs out of target range) associated with different factor scores, especially the Maintain High BG factor, the magnitude of these differences was modest and their clinical implications need further study.

Despite these shortcomings, the findings demonstrate that FoH in pediatric T1D is a complex construct and that the CHFS and PHFS reflect several different affective and behavioral components of FoH, which are similar in children and parents. Based on these findings, it appears that the four PHFS and CHFS factors should be treated and scored as independent subscales to assess these different components of FoH. However, given the low internal consistency of the Avoidance subscale due to the diverse behaviors represented, clinicians are encouraged to review these items separately to identify potentially problematic behaviors. It is also recommended that items be scored on the factor on which they loaded, even when the item falls on different factors for youth and parents, including the Behavior Subscale item (Eat large snacks at bedtime), which loaded onto a Worry Subscale factor (Helplessness) for youth. Some researchers may prefer to follow the traditional method of computing Worry and Behavior Subscale scores, especially when comparing results to other studies, but the fact that this is not the best fitting model should be kept in mind. From a clinical perspective, use of the factor scores will provide a more comprehensive assessment of FoH and valuable information about specific problem areas for individual families. This additional information can also help guide decisions concerning the types of interventions indicated to reduce problematic FoH. For
example, the appropriate treatment approach for youth who engage in diabetes management behaviors aimed at keeping BG levels high in order to avoid hypoglycemia would differ greatly from interventions for those who are extremely anxious about episodes occurring when alone or away from parents. This approach to using the CHFS and PHFS in assessment and treatment planning will more accurately reflect the complexity of affective and behavioral responses to the problem of pediatric hypoglycemia.

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References


