Psychometric Properties of the Hypoglycemia Fear Survey in a Clinical Sample of Adolescents with Type 1 Diabetes and Their Caregivers

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Abstract

Objective A previously published exploratory factor analysis suggested that the Hypoglycemia Fear Survey—Child and Parent Versions, is comprised of three subscales: Maintain High Blood Glucose, Helplessness/Worry About Low Blood Glucose, and Worry About Negative Social Consequences. The primary aim of this study was to confirm this three-factor model with a clinical population of adolescents with type 1 diabetes (T1D) and their caregivers. **Methods** Participants included N = 1,035 youth ages 10–17.99 years with T1D, and their female (N = 835) and/or male (N=326) caregivers who completed the Hypoglycemia Fear Survey independently during a routine medical appointment. We conducted confirmatory factor analysis and examined reliability of the Hypoglycemia Fear Survey and its associations with demographics and clinical outcomes (e.g., mean blood glucose, glycemic control). Results Confirmatory factor analysis supported the three-factor model in youth and female and male caregivers. The internal consistencies for Maintain High Blood Glucose, Helplessness/Worry About Low Blood Glucose, and Worry About Negative Social Consequences were acceptable. The majority of demographic and clinical outcome variables correlated as hypothesized with the three subscales. **Conclusions** Using a large clinical sample of adolescents with T1D and their caretakers, we confirmed the three-factor model for the Hypoglycemia Fear Survey, which is sufficiently reliable to be used in a clinical setting. Important areas of future research include examining moderators for the effect of fear of hypoglycemia on clinical outcomes, and possible inclusion of items related to modern diabetes devices.

Key words: adherence/self-management; adolescents; anxiety; diabetes; parent psychosocial functioning; psychosocial functioning.

Introduction

Type 1 diabetes (T1D) is an autoimmune disease requiring engagement in multiple self-management behaviors (e.g., monitor blood glucose levels, count carbohydrates, administer exogenous insulin) on a daily basis to compensate for the body's inability to produce insulin and regulate blood glucose levels. A common acute T1D complication is hypoglycemia (i.e., low blood glucose) which occurs when there is a mismatch between blood glucose levels and the amount of insulin administered, or when an individual is extra sensitive to insulin, such as during physical activity. Symptoms of hypoglycemia may include sweating, irritability, confusion, increased heart rate, dizziness, and shakiness, which may also be symptoms of anxiety. Other symptoms unique to hypoglycemia include chills and extreme hunger. In its severe form, hypoglycemia results in the need for assistance from another individual to administer fast-acting glucose and without treatment, it may lead to seizure, coma, or death. If physical symptoms are repeatedly paired with both (a) episodes of hypoglycemia and (b) episodes of anxiety, individuals may be at risk for developing fear of hypoglycemia based on classical conditioning principles. Further, the overlap in symptoms between hypoglycemic episodes and intense anxiety can make it difficult for individuals to differentiate the cause of onset of physical symptoms.

Adaptive worry about the occurrence of low blood glucoses motivates an individual to monitor blood glucose levels and to be prepared to respond to hypoglycemia (e.g., carry fast-acting glucose). In contrast, one type of anxiety that causes functional impairment or has deleterious effects on T1D self-management behaviors, glycemic control, and quality of life is referred to as fear of hypoglycemia (FOH), and as a specific phobia of low blood glucose (Ahola et al., 2016; Kent & Quinn, 2018; Martyn-Nemeth et al., 2017; O'Donnell et al., 2019). Cognitive manifestations of FOH may include frequent, intense, or excessive worry or anxiety about low blood glucoses. The behavioral manifestations are particularly problematic if there is engagement in behaviors to purposefully maintain high blood glucose including administering less than recommended amounts of insulin or refusing to engage in physical activity (Barnard et al., 2010; O'Donnell et al., 2019), or extremely frequent glucose checking, awaking in the night multiple times to check blood glucoses, and eating before bed when not needed.

The American Diabetes Association's Medical Standards of Care and Position Statement on Psychosocial Care for Persons with Diabetes recommends routine screening using scientifically validated questionnaires for psychological conditions including anxiety (e.g., FOH, needle phobia, generalized

anxiety), depression, diabetes distress, and disordered eating behaviors (American Diabetes Association, 2021; Young-Hyman et al., 2016). Many studies focus on screening for depression as part of routine T1D medical appointments (Barry-Menkhaus et al., 2020; Majidi et al., 2020; Mulvaney et al., 2021; Wolfgram et al., 2020), but studies on anxiety are less common as is routine clinical assessment of FOH using scientifically validated questionnaires. The most common questionnaires used to assess FOH are the Hypoglycemia Fear Surveys that include child (ages 6-18) (Gonder-Frederick et al., 2006; Green et al., 1990), parent of children (ages 6-18) (Clarke et al., 1998; Cox et al., 1987), and parents of young children (ages 2-8) versions (Patton et al., 2008). The Hypoglycemia Fear Surveys have been used primarily in research, with little published data as to their utility in clinical settings.

All Hypoglycemia Fear Survey versions yield a Total Score and two subscale scores-Behavior and Worry; however, only reliability and validity statistics were provided in the original study and factor analysis was not conducted (Gonder-Frederick et al., 2006). Therefore, Shepard et al. (2014) subjected the Child and Parent versions of the Hypoglycemia Fear Survey to an exploratory factor analysis to better understand the construct of FOH in pediatrics (Gonder-Frederick et al., 2006). Two subscales within Behavior (Maintain High Blood Glucose, Avoid/Prevent Low Blood Glucose) and two subscales within Worry (Helplessness/Worry About Low Blood Glucose, Worry About Negative Social Consequences) were revealed (Shepard et al., 2014). The reliability of the Avoid/Prevent Low Blood Glucose subscale was not as strong as the other subscales and many of the items represent appropriate and medically recommended behaviors to prevent or treat low glucose levels. In fact, parents scoring in the highest tertile of Avoid/ Prevent Low Blood Glucose had children with lower A1C (i.e., average blood glucose during prior 2.5-3 months; Blanc et al., 1981) than parents scoring in the lowest tertile (Shepard et al., 2014), calling into question whether it captures FOH behaviors as originally intended.

Limitations of the Shepard et al. (2014) study include data that were derived from several research studies in which families were required to check blood glucose 4 times per day and youth had an average A1C of 8.1%, which was lower than the national average of 8.6% at that time (Cengiz et al., 2013). Only 12% of parents were fathers and the racial/ethnic distribution of parents was 93% Caucasian, 4% African-American, and 2% Hispanic. Taken together, the sample used to identify the three new Hypoglycemia Fear Survey subscales cannot be assumed to replicate in a heterogenous clinical sample. Thus, the primary aim of the current study was to use confirmatory factor analysis to assess whether the three subscales identified by Shepard et al. (2014) could be replicated in a large, more diverse (e.g., higher percentage of Hispanic/Latino participants and fathers), clinical sample of youth with T1D and their caregivers. First, we hypothesized that the three factors (i.e., subscales) of the Hypoglycemia Fear Survey would demonstrate adequate fit when subjected to confirmatory factor analysis in a clinical sample of youth and their caregivers. Second, we hypothesized that female youth would experience more worry than male youth given that females have higher rates of anxiety than males (Kessler et al., 2008; Wittchen et al., 1994). Third, we hypothesized that female caregivers would experience more FOH than male caregivers (Haugstvedt et al., 2010; Patton et al., 2008). Finally, we hypothesized that there would be no differences in FOH when comparing younger youth (10–12 years) to older youth (13–17 years), but caregivers of younger youth would experience higher FOH than caregivers of older youth (Gonder-Frederick et al., 2011). We did not make any hypotheses about insulin pump or continuous glucose monitor (CGM) use because findings from the limited existing literature are mixed on the associations between technology and FOH (Al Havek et al., 2015; Barnard et al., 2014; Gonder-Frederick et al., 2006; Ng et al., 2019; Van Name et al., 2018; Ziegler et al., 2015).

Two exploratory aims were also examined. First, the psychometric properties of the Avoid/Prevent Low Blood Glucose subscale were examined in a clinical sample given this subscale's history of poor internal reliability and correlations with positive clinical outcomes (Patton et al., 2008; Shepard et al., 2014). Second, associationsbetween the subscales and clinical outcomes including mean blood glucose, A1C, percentage of readings from meter or pump <70 mg/dL, 70–180 mg/dL, >180 mg/dL were examined.

Methods

Participants and Procedures

Participants were youth ages 10–17.99 years with T1D and their female and/or male caregivers who completed the Hypoglycemia Fear Survey independently during routine medical appointments at the University of Colorado's Barbara Davis Center for Diabetes. The Hypoglycemia Fear Surveys were incorporated into routine care as recommended by the American Diabetes Association. Data were entered into each participant's medical chart. For the purposes of the current study, the University of Colorado Multiple Institution Review Board granted approval for the clinical data to be used.

Measures

Sample Characteristics

Demographic and T1D clinical characteristics were extracted from electronic medical records: age, sex, race/ethnicity, type of insurance, A1C at date of questionnaire completion, T1D duration, insulin delivery method (multiple daily injections vs. insulin pumps), and CGM use. Diabetes devices were downloaded at routine T1D clinic visits and metrics reflect the 14 days prior to the clinic visit depending on devices used: (a) average number of blood glucose checks per day; (b) mean blood glucose; (c) percentage blood glucoses low (<70 mg/dL), in target range (70–180 mg/dL), and high (>180 mg/dL) (Bergenstal et al., 2013); (d) average number of insulin boluses administered per day (insulin pump users only); and (e) blood glucose standard deviation (CGM users only).

Glycemic Control

Hemoglobin HbA1c (A1C) was collected at point of care using a Siemens Healthcare Diagnostics DCA Vantage (reference range 4.2–6.5%).

Fear of Hypoglycemia

FOH was assessed using the child and parent versions of the Hypoglycemia Fear Survey (Cox et al., 1987; Gonder-Frederick et al., 2006). All items are rated on a 5-point Likert scale (0 = "never" to 4 = "almost always"). The Maintain High Blood Glucose subscale (score range = 0-12) assesses the extent to which an individual engages in behaviors to prevent hypoglycemia by purposefully maintaining blood glucose levels higher than medically recommended. The Helplessness/Worry About Low Blood Glucose subscale (score range = 0-21) assesses worry about hypoglycemia and related feelings of helplessness such as having a low blood glucose while asleep. The Worry About Negative Social Consequences subscale (score range = 0-24) assesses worry about social consequences of hypoglycemia such as doing something embarrassing (Shepard et al., 2014). Finally, the Avoid/ Prevent Low Blood Glucose subscale (score range = 0-40) assesses behaviors to prevent having low blood glucoses and safely treat them if they occur.

Data Analytic Plan

Primary data analyses are presented separately for youth and caregivers (i.e., combined male and female caregivers). Descriptive statistics including means, standard deviations, ranges, and frequencies were calculated using SPSS version 27. Pearson (continuous variables) and Spearman (continuous and categorical) correlations were used to examine relationships between variables. Confirmatory factor analyses were performed using SPSS version 27 Amos, separately for youth and caregivers, using maximum likelihood estimation. The following criteria were used to assess model fit: Comparative Fit Index (CFI) >0.90, Tucker Lewis Index (TLI) >0.90, and Root Mean Square Error of Approximation (RMSEA) <0.08 (Browne & Cudeck, 1992; Marsh et al., 2004). Chi-square fit indices were not used because large sample sizes tend to produce non meaningful statistical significance (Kline, 2013). Cronbach's alpha was used to assess internal consistency of each Hypoglycemia Fear Survey subscale. Independent samples t-tests were used to explore group differences on subscales scores across demographic (e.g., respondent sex, age of child) and clinical characteristics (e.g., use of insulin pump and/ or CGM). The associations between Hypoglycemia Fear Survey subscale scores, T1D self-management behaviors (i.e., blood glucose checks per day, insulin boluses per day), T1D clinical outcome variables (i.e., mean blood glucose, A1C, percentage of readings from meter or pump <70 mg/dL, 70-180 mg/dL,>180 mg/dL) were analyzed by dividing subscale scores into tertiles to compare those with the highest and lowest Hypoglycemia Fear Survey subscale scores. Independent t-tests compared T1D self-management behaviors and clinical outcomes for those with the highest and lowest scores on each of the Hypoglycemia Fear Survey subscales.

Results

Descriptive Characteristics and Correlations

A total of 1,035 youth (N = 543 male; 52.5%) and their female (N = 835; 71.9%) and/or male (N = 326; 28.1%) caregivers participated in this study. The racial/ethnic distribution of the sample was 82.7% (n = 768) Caucasian; 4.7% (n = 44) Black; 12.8% (n = 117) Hispanic or Latino, 4.4% Multiracial which is representative of the general U.S. T1D population (Foster et al., 2019), and the Barbara Davis Center's population (70% Caucasian, 4.1% Black, 17.8% Hispanic/Latino, 3.9% Multiracial). A total of 30% of our sample received government insurance, whereas 36.2% of the Barbara Davis Center's 10-17-year-old patients receive government insurance. Sample characteristics, descriptive statistics, and correlations among all variables for youth and caregivers are found in Table I. These same statistics are presented separately for male and female caregivers in Supplementary Table 1.

Psychometric Properties of the Maintain High Blood Glucose, Helplessness/Worry about Low Blood Glucose, and Worry about Negative Social Consequences Subscales

Confirmatory Factor Analysis

The fit statistics for youth and caregiver samples on the Maintain High Blood Glucose, Helplessness/ Worry About Low Blood Glucose, and Worry About Negative Social Consequences subscales were acceptable (Table II) and standardized factor loadings for every item are displayed in Table III. Correlations among subscales for each respondent (i.e., youth and caregivers) were positively correlated (all ps < .001); see Table I. Supplementary Table 2 contains factor loadings separately for male and female caregivers.

Internal Reliability

Cronbach alphas for the three subscales for youth were acceptable to good: 0.78 (Maintain High Blood Glucose), 0.81 (Helplessness/Worry About Low Blood Glucose), and 0.72 (Worry About Negative Social Consequences). For caregivers, the Cronbach alphas were also acceptable to good: Maintain High Blood Glucose (0.83), Helplessness/Worry About Low Blood Glucose (0.90), and Worry About Negative Social Consequences (0.78).

Differences in Subscale Scores Based on Respondent Characteristics and Clinical Outcomes

Sex

There were no differences between female and male youth on Maintain High Blood Glucose. However, female youth $(M = 8.6 \pm 6.2)$ reported significantly higher scores than male youth $(M = 6.9 \pm 5.4)$ on Helplessness/Worry About Low Blood Glucose (t(939) = 4.6, p < .001) and Worry About Negative Social Consequences (Female $M = 4.2 \pm 3.7$ vs. Male $M = 3.3 \pm 3.1$; t(936.2) = 4.1, p < .001). There were no differences between female and male caregivers on Maintain High Blood Glucose or Worry About Negative Social Consequences. Female caregivers $(M = 15.7 \pm 8.7)$ reported significantly higher scores than male caregivers $(M = 12.5 \pm 6.9)$ on Helplessness/Worry About Low Blood Glucose (t(699.6) = 6.3, p < .001).

Youth Age

There were no significant group differences between younger (10–12 years) and older (13–17 years) youth on any subscales. Caregivers of younger youth $(M = 4.3 \pm 2.6)$ reported higher scores than caregivers of older youth $(M = 3.6 \pm 2.6)$ on Maintain High Blood Glucose (t(1,108) = 4.4, p < .001). Group differences were not significant for caregivers on either Helplessness/Worry About Low Blood Glucose or Worry About Negative Social Consequences based on youth age.

Insulin Pump Use

Youth using multiple daily injections ($M = 3.8 \pm 2.9$) had higher scores than those using an insulin pump ($M = 3.4 \pm 2.8$; t(993) = 2.1, p = .039) only on the

	Υοι	1000000000000000000000000000000000000	(35)		Ca	regivers (N =	1,161)
	<i>M</i> (sd); range or <i>N</i> (%)	Maintain high	Helplessness	Social consequences	Maintain high	Helplessness	Social consequences
Maintain high BG	_		_	_	_	_	_
Worry/helplessness		0.26***	_	_	0.30***	_	_
Worry/social consequences	_	0.26***	0.65***		0.19***	0.55***	—
Age (years)	13.9 (2.3); 10.0–18.0	0.08*	0.03	0.02	-0.17***	0.03	-0.01
Sex (male youth)	543 (52.5%)	-0.31	-0.15***	-0.12***	0.01	0.01	-0.01
White	768 (82.7%)	0.01	-0.07*	-0.06	0.07*	0.02	-0.07*
Hispanic	117 (12.8%)	-0.03	0.02	-0.01	-0.07*	0.01	0.03
Commercial insurance	727 (70%)	-0.03	-0.05	-0.12**	0.06*	0.09**	-0.06*
T1D duration (years)	5.4 (3.9); 0.1–17.3	-0.01	-0.03	-0.05	-0.02	0.00	-0.06
A1C	9.0% (2.1); 4.9–15.0%	0.06	0.0	0.02	-0.08**	-0.02	0.08**
Uses pump	614 (59%)	-0.07*	-0.01	-0.01	-0.1	0.05	-0.04
Uses CGM	437 (42%)	-0.02	0.04	-0.01	0.13***	0.16***	-0.02
BG checks/day	4.1 (2.4); 0.0–14.6	0.01	0.04	0.03	0.12**	0.06	0.02
Mean BG	223.0 (64.2); 80.9-473.0	0.09*	0.03	0.0	-0.00	0.00	0.05
Boluses/day	5.5 (2.7); 0.0–15.4	-0.13**	-0.01	-0.02	0.06	0.06	-0.07
% BG readings low	4.1 (5.3); 0.0-40.0	-0.01	-0.03	-0.01	0.00	0.01	-0.03
% BG readings in-range	31.0 (20.7); 0.0–96.0	-0.12**	-0.08	-0.03	-0.05	-0.03	-0.03
% BG readings high	64.4 (22.8); 0.0–100.0	0.08*	0.05	-0.02	0.01	0.01	0.01
CGM Mean BG	186.4 (40.7); 68.0-371.0	0.08	0.09	0.08	0.06	0.11*	0.06
% time on sensor	75.6 (24.8); 0.0–100.0	-0.16*	-0.08	-0.02	0.07	-0.06	-0.07
Sensor SD	66.7 (19.2); 0.0–108.0	0.1	0.06	0.06	0.09	0.05	0.01
% low CGM	2.3 (3.7); 0-54.0	-0.01	-0.04	0.0	-0.07	-0.05	-0.02
% high CGM	51.3 (21.8); 0.0-100.0	0.13*	0.08	0.10	0.05	0.08	0.09
M (SD)	· · · · · ·	3.6 (2.8)	7.7 (5.9)	3.7 (3.4)	3.9 (2.6)	14.8 (8.4)	3.3 (3.5)

 Table I. Means and Standard Deviations for T1D Self-Management Behaviors and Correlations Among Hypoglycemia Fear

 Survey Subscale Scores, Demographic Variables, and T1D Clinical Characteristics

Note. BG = blood glucose; CGM = continuous glucose monitor; T1D = type 1 diabetes.

*p < .05.

**p < .01.

***p < .001.

Table II. Confirmatory Factor Analyses Fit Indices on theHypoglycemia Fear Surveys

	Adolescents	Caregivers
RMSEA	0.07	0.07
CCFI	0.89	0.91
TLI	0.86	0.89

Note. RMSEA = root mean square error of approximation; CFI = comparative fit index; TLI = Tucker–Lewis index.

Maintain High Blood Glucose. There were no significant differences on any other subscale for youth or caregivers based on whether the child used an insulin pump or multiple daily insulin injections.

CGM Use

There were no significant differences for youth scores on the three subscales based on CGM use. Caregivers whose child used a CGM scored higher on Maintain High Blood Glucose ($M = 4.3 \pm 2.6$) compared to those whose child did not use a CGM ($M = 3.6 \pm 2.6$, t(1,109) = -4.4, p < .001) as well as on Helplessness/ Worry About Low Blood Glucose ($M = 16.1 \pm 8.0$ vs. $M = 13.8 \pm 8.5$, (t(1,122) = -4.8, p < .001).

T1D Device and Clinical Outcomes

Although not all group differences were statistically significant, the overall pattern observed in youth was that those in the highest tertile for all three subscales had worse T1D device and clinical outcomes compared to those in the lowest tertiles. All statistics are included in Table IV for youth and caregivers; Supplementary Table 3 contains separate analyses for male and female caregivers.

The pattern of group differences in T1D device and clinical outcome variables for caregivers was not as consistent as the pattern observed in youth. As expected, caregivers in the highest tertile of Maintain High Blood Glucose and Helplessness/Worry About Low Blood Glucose had children with a significantly greater number of blood glucose checks per day. In contrast, caregivers who scored in the highest tertile of Worry About Negative Social Consequences had children who administered significantly fewer insulin boluses per day and had higher A1Cs compared to children of caregivers who scored in the lowest tertile of Worry About Negative Social Consequences. Caregivers in the highest tertile for Maintain High Blood Glucose had children with significantly lower

		Youth			Caregive	r
	Maintain high	Worry helplessness	Social consequences	Maintain high	Worry helplessness	Worry social consequences
Keep BG high	0.69			0.69		
Keep BG higher when alone	0.81			0.90		
Keep BG higher when away	0.70			0.80		
Not recognizing low		0.41			0.55	
Not having food when BG goes low		0.50			0.65	
Feeling dizzy in public		0.61			0.71	
Low BG while asleep		0.54			0.73	
Embarrassing self			0.70			0.49
Low BG when alone		0.55			0.81	
Looking stupid/clumsy			0.64			0.56
Losing control due to low BG		0.71				0.66
No one around to help		0.67			0.78	
Making a mistake at school			0.72			0.75
Trouble at school due to low BG symptoms			0.61			0.69
Having seizures		0.50			0.66	
Getting long-term complications from low BG		0.60			0.64	
Feeling woozy when BG is low		_			0.68	
Having a low			0.34		0.68	
Cronbach alpha	0.78	0.81	0.72	0.83	0.90	0.78

Table III. Factor Loadings for Clinical Sample Based on Three Factor Model

Note. BG = blood glucose.

A1C compared to those in the lowest tertile. To better understand why caregivers in the highest tertile had youth with lower A1Cs, we examined two additional variables: age of youth and T1D duration. Analyses of covariance, one controlling for youth age and the other for T1D duration, revealed that the A1C group difference persisted (p < .01 and p < .001, respectively). All statistics are included in Table IV.

Psychometric Properties of Avoid/Prevent Low Blood Glucose Subscale

Internal reliabilities of the Avoid/Prevent Low Blood Glucose subscales were poor: Cronbach alphas = 0.59for youth, 0.69 for caregivers. Across youth (t(423.1) =3.8, p < .001), and caregivers (t(632.1) = 4.5, p < .001), those in the highest tertile of Avoid/Prevent Low Blood Glucose had significantly lower A1Cs. Youth (t(509) =-3.2, p < .01) and caregivers (t(572.1) = -4.1), p < .001) in the highest tertile for Avoid/Prevent Low Blood Glucose checked blood glucose more frequently (or have youth that checked blood glucose more frequently) than those in the lowest tertile. Caregivers in the highest tertile for Avoid/Prevent Low Blood Glucose also had youth with lower mean blood glucose (t(551.2)) = 3.9, p < .001), lower % readings >180 mg/dL (t(613)) = 3.5, p < .01), but greater % of readings < 70 mg/dL(t(611) = -2.1, p < .05).

Discussion

This study is the first to confirm the psychometric properties of the Maintain High Blood Glucose, Helplessness/Worry About Low Blood Glucose, and Worry About Negative Social Consequences subscales of the Hypoglycemia Fear Surveys in a very large clinical sample of youth with T1D and their female and male caregivers. The three-factor model in our clinical sample is consistent with the three-factor model found in a research sample (Shepard et al., 2014). Therefore, the Hypoglycemia Fear Surveys are appropriate for assessing symptoms of FOH as part of routine clinical care of youth with T1D and their caregivers.

Further, the three factors correlated as hypothesized with demographic and clinical outcome variables. However, there was one notable exception which is that caregivers in the highest tertile of Maintain High Blood Glucose had youth with lower A1Cs than caregivers in the lowest tertile, which may be explained by adolescent CGM use. For example, caregivers with greater Maintain High Blood Glucose scores may be motivated for their adolescent to use a CGM, which is associated with lower A1C (Beck et al., 2019b). Alternatively, access to CGM data may facilitate caregiver involvement in T1D management, which is also associated with lower A1C (Anderson et al., 1990, 1997).

The Avoid/Prevent Low Blood Glucose subscale demonstrated poor internal consistency for the child and parent versions of the Hypoglycemia Fear Survey. Nevertheless, higher youth and caregiver scores were associated with better clinical outcomes including lower A1C, fewer blood glucose readings >180 mg/ dL, and lower mean blood glucose. The differences in A1C for the highest compared to lowest tertiles on the

Table IV. Means and Standard Deviations for T1D Self-Management Behaviors and Clinical Outcomes for the Lowest and Highest Tertiles on the Hypoglycemia Fear Survey Subscales	dard Deviations	for T1D Self-Ma	nagement Be	haviors and Clinica	al Outcomes for the	Lowest and I	Highest Tertiles	on the Hypoglyc	emia Fear Survey
Youth hypoglycemia fear survey	rvey								
Clinical outcome	Maint: Lowest	Maintain high blood glucose st Highest t	cose t-value	Helplessness/v Lowest	Helplessness/worry about low blood glucose Lowest Highest t-valı	d glucose t-value	Worry al Lowest	Worry about negative social consequences west Highest t-value	l consequences t-value
A1C (%)	9.0 (2.1)	9.1 (2.1)	-1.0	9.0 (2.2)	9.0 (2.0)	0.2	9.1 (2.2)	9.1 (2.0)	0.0
Blood glucose meter or insulin pump data Mean BG (mg/dL) 219.3 (62.5)	ın pump data 219.3 (62.5)	229.4 (66.3)	-1.8	219.6 (68.3)	225.5 (62.9)	-1.1	186.9	191.4 728 7	-0.3
% readings <70 mg/dL	3.7 (4.5)	3.9(5.1)	-0.5	3.9 (5.4)	4.0 (4.7)	-0.2	(47.6) 3.8 (4.9)	(38.7) 3.9 (4.5)	-0.2
% readings 70-180 mg/dL	33.1 (21.6)	28.2 (19.3)	2.2*	35.1 (23.3)*	28.9 (19.7)*	2.6*	32.1 (21.9)	30.4 (20.2)	0.7
% readings $>180 \mathrm{mg/dL}$	(63.7(22.3))	66.5(22.4)	-1.4	62.4 (24.2)	(55.9(22.1))	-1.8	(55.0(22.5))	64.8 (22.4)	0.1
טט cnecks/day Boluses/day	4.1 (2.4) 5.8 (2.6)	4.1(2.4) 5.0(2.6)	0.4 2.6**	4.0(2.4) 5.7(2.8)	4.5(2.5) 5.3(2.5)	$^{-1.0}$ 1.2	4.0 (2.3) 5.7 (2.7)	4.2(2.5) 5.4(2.5)	$^{-1.0}$
CGM data Mean BG (mg/dL)	184.8 (44.6)	192.6 (43.5)	-1.3	183.2 (45.0)	190.6 (42.0)	-1.3	186.9	191.4	-0.8
			1			1	(47.6)	(38.7)	1
% time <70 mg/dL	2.7(5.7)	1.8 (2.2)	1.5	1.9(2.5)	2.0 (2.3)	-0.3	2.3 (2.5)	2.4(5.1)	-0.1
% time 70–180 mg/dL	49.0 (21.1)	42.8 (21.2)	2.1^{*}	48.5 (22.4)	45.1(21.5)	1.2	47.6 (21.6)	43.0(19.6)	1.7
% time >180 mg/dL	48.4 (22.4)	55.4 (21.9)	2.3*	49.2 (23.2)	52.9 (22.1)	-1.2	50.1 (22.4)	54.7 (20.8)	-1.6
Caregiver hypoglycemia fear survey	· survey								
	Maint: Lowest	Maintain high blood glucose st Highest t	cose t-value	Helplessness/v Lowest	Helplessness/worry about low blood glucose Lowest Highest	d glucose	Worry al Lowest	Worry about negative social consequences west Highest t-value	l consequences t-value
AIC	9.2 (2.3)	8.6 (1.8)	3.5***	8.9 (2.1)	8.8 (1.9)	0.88	8.7 (2.0)	9.0 (2.1)	-2.5*
blood glucose or insulin pump data Mean BG (mg/dL) 223.2	np data 223.2 (70.3)	220.4 (61.9)	9.6	225.2 (71.4)	222.5 (65.2)	0.5	214.7	222.4	-1.4
% readings <70 mg/dL	4.1 (5.2)	4.0(5.1)	0.0	3.8 (4.8)	4.1(5.4)	-0.8	4.0 (4.7)	4.1(5.2)	-0.3
% readings 70–180 mg/dL	32.8 (22.8)	30.4(17.9)	1.2	32.0 (22.9)	31.1(18.6)	0.4	33.4 (22.6)	31.1(20.6)	1.1
% readings >180 mg/dL	63.5 (24.8)	63.6(21.0)	-0.1	64.1(25.0)	63.8(21.0)	0.2	62.7 (23.5)	63.2 (23.7)	-0.3
BG checks/day	3.9 (2.2)	4.4 (2.5)	-3.2**	3.9 (2.2)	4.3 (2.5)	-2.1*	4.1(2.5)	4.3(2.5)	-0.5
Boluses/day CGM data	5.3 (4.2)	6.1(3.3)	-2.0°	5.3 (2.7)	5.6 (3.2)	-0.85	6.0 (4.4)	5.2 (2.6)	2.1^{*}
Mean BG (mg/dL)	184.2 (40.7)	186.6(39.5)	-0.6	183.2 (35.2)	190.8(40.4)	-1.6	184.3	185.8	-0.3
% time <70 mg/dL	23 (25)	2.0 (2.7)	0.8	2.7(3.0)	2.1 (2.7)	1.6	(42.1) 2.2 (2.6)	(40.8) 2.4 (2.9)	-0.7
% time 70–180 mg/dL % time >180 mg/dL	47.2 (22.1) 50.3 (23.0)	46.5(30.5) 51.4(20.9)	0.3 - 0.5	46.8 (20.1) 50.5 (20.7)	44.5 (19.5) 53.3 (20.2)	$0.94 \\ -1.1$	48.7 (21.6) 49.0 (22.4)	45.7(22.1) 51.9(22.7)	-1.1
Note $BG = blood ellicose^{2}h < 1$	1								

Note. BG = blood glucosep < .1. *p < .05. **p < .01. **p < .01.

Avoid/Prevent Low Blood Glucose subscale are large enough to be considered clinically meaningful (-0.7%for both female and male caregivers and -0.5% for youth) given that a 0.5% change in A1C is considered clinically meaningful (Beck et al., 2019a). Taken together, there is a need to develop additional items for the Avoid/Prevent Low Blood Glucose subscale to improve its reliability given its usefulness as a subscale of adaptive functioning.

The Avoid/Prevent Low Blood Glucose subscale assesses important adaptive behaviors, but because of its poor psychometric properties, items need to be revised if it is to be used as a subscale. Moreover, if these items continue to be included in the administration of the Hypoglycemia Fear Surveys, they should neither be used to calculate a Behavior subscale score, nor should they be used in the calculation of a Total score. As Shepard et al. (2014) suggested, items on the Avoid/Prevent Low Blood Glucose subscale should be queried individually to ensure that youth and their caregivers engage in adaptive and medically recommended behaviors to prevent lows and to treat them when they occur. Finally, the psychometric analyses show that the maladaptive behavioral components of FOH are better represented by the three items on the Maintain High Blood Glucose subscale with the best fit.

Our understanding of the relationship between diabetes technology and FOH is constantly evolving as an increasing number of individuals adopt technology to assist with T1D management (Foster et al., 2019). It is possible that diabetes technology, such as CGMs and their constant source of data about blood glucose levels, significantly alters an individual's experience of FOH. Newer technologies for T1D management, including closed-loop systems (i.e., CGM and insulin pump communicate), may reduce FOH (Bisio et al., 2021; Cobry et al., 2021; Youngkin et al., 2020). However, variability in how the Hypoglycemia Fear Survey is scored (i.e., inclusion of Avoidance items) makes it is difficult to discern if parents decreased behaviors to purposefully maintain high blood glucoses or if they increased engagement in adaptive behaviors (e.g., carrying fast-acting glucose) and which of these are most associated with hypoglycemia avoidance.

The sample of youth included in Shepard et al. (2014) were recruited from research studies between 2002 and 2010, and consisted of 40% insulin pump users. Significant improvements in the previous decade and more so in the last 5 years have been made to insulin analogs and pump algorithms with 63% of youth currently using an insulin pump (Foster et al., 2019). Its use is negatively associated with frequency of severe hypoglycemia (Karges et al., 2017), which may further impact how an individual experiences FOH as

evidenced by lower behavioral manifestations of worry in our clinical sample of youth who use insulin pumps.

The Hypoglycemia Fear Surveys are in need of modifications in two areas. First, in its current form, items on the Hypoglycemia Fear Surveys do not assess behavior or worry in the context of modern diabetes technology. There are no items to assess behaviors such as suspending or removing an insulin pump or worry about accuracy of CGM readings. Notably, there are also no items pertaining to whether adolescents worry about devices alarming when blood glucose is low or trending low and the subsequent social implications (e.g., people staring, becoming annoved) despite this being a frequent concern raised by adolescents in our clinical encounters. Items do not assess one's trust in the algorithms used by hybrid closed loop systems to discontinue delivery of insulin when the individual is predicted to experience hypoglycemia. Not only is future research needed to better understand how modern diabetes management affects FOH, but updating the Hypoglycemia Fear Surveys to include an additional subscale related to technology is recommended. interpretation Second, of Hypoglycemia Fear Survey subscales is limited by the continuous nature of the scores with higher scores indicating greater fear of hypoglycemia. Without a clinical cut point, clinicians do not know at what score a recommendation for additional evaluation should be made. Therefore, there is a critical need to establish a clinical cut point for each subscale to further increase the clinical utility of the Hypoglycemia Fear Surveys. As soon as clinical cut points are determined, any clinician with appropriate training for scoring and interpretation may provide feedback to youth with T1D and their caregivers about their scores on the Hypoglycemia Fear Surveys.

Additional considerations for future research include examining psychometric properties (e.g., testretest), longitudinal patterns, and additional convergent validity using questionnaires and standardized interviews that assess generalized anxiety in both caregivers and youth. Although the racial/ethnic distribution is representative of the T1D population overall, future research should address validation of the Hypoglycemia Fear Surveys in under-represented minorities and those with lower socioeconomic status. However, given the relatively small percentages of racial/ethnic minorities in the overall T1D population, a large multi-site study will be required.

Strengths of the current study include completion of the Hypoglycemia Fear Surveys as part of routine clinical care in a busy T1D clinic in which all youth with T1D and their female and male caregivers were given the opportunity to be screened, which also increases generalizability. Further, youth and caregivers were representative of the general T1D population (Foster et al., 2019) although collecting demographic data via medical chart review resulted in some missing data, especially race and ethnicity. Finally, the large sample size in this study also increases generalizability and adds confidence in the confirmatory factor analyses (Wolf et al., 2013). Study findings must also be considered in the context of its limitations. We were unable to examine sensitivity of the Hypoglycemia Fear Survey as there is no goldstandard diagnostic measure or interview to assess FOH and hypoglycemia history was not collected. An additional limitation is that the sample included only youth between 10 and 17 years of age and their caregivers because these data were collected as part of piloting psychosocial screening during routine clinical care for patients >10 years of age. The parent and child versions of the Hypoglycemia Fear Surveys can be administered to children as young as 6 years old. Therefore, examining the psychometric properties of the Hypoglycemia Fear Surveys in children between 6 and 10 years old and their caregivers in future research is warranted as it is possible that younger children and their caregivers have unique fear and/or different patterns of subscales. Overall, the results of this study provide evidence of the clinical utility of the Hypoglycemia Fear Surveys to assess worry or anxiety about hypoglycemia as recommended by the American Diabetes Association.

Supplementary Data

Supplementary data can be found at: https://academic.oup. com/jpepsy.

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