

# Psychometric Properties of the Problem Areas in Diabetes: Teen and Parent of Teen Versions

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Author Note: PAID-T and P-PAID-T measures are available from the authors on request.

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## Abstract

**Objective** This study adds to the literature on the psychometric properties of the Problem Areas in Diabetes-Teen (PAID-T) and Parent (P-PAID-T) Versions. It also aims to shorten the measures of diabetes-specific distress, determine construct validity, and establish cutoff scores.

**Methods** Data are from two independent studies ( $N = 1,265$ ). Adolescent-caregiver dyads completed measures of emotional distress, diabetes strengths, hemoglobin A1c, blood glucose checks, and average blood glucose. Exploratory and confirmatory factor analyses assessed factor structures for each measure. Correlational analyses provided support for concurrent validity. Receiver-operating characteristic curves identified cutoff scores based on clinically meaningful groups identified with latent profile analysis. **Results** Analyses supported a 14-item PAID-T and a 15-item P-PAID-T, with preliminary cutoff scores  $\geq 44$  and  $\geq 54$ , respectively. Measures were associated with emotional and health outcomes as hypothesized. **Conclusions** The PAID-T and P-PAID-T are valid, reliable, and useful measures of diabetes-specific distress for teenagers with type 1 diabetes and parents of teenagers.

**Key words:** adolescent; diabetes mellitus, type 1; emotional stress; surveys and questionnaires.

Adolescence is a period marked by developmental changes, increased independence, and greater attention to peer relationships (Larson & Verma, 1999). This developmental period can be difficult for teens with type 1 diabetes (T1D) who face unique challenges that accompany daily diabetes management. Diabetes-specific challenges may include the chronic and demanding nature of diabetes management, negative feelings about out-of-range blood glucose numbers, and conflict with parents around diabetes adherence and monitoring (Davidson, Penney, Muller, & Grey, 2004). During

adolescence, adherence, and parental monitoring for diabetes tasks declines (Main et al., 2014) and glycemic control worsens (Miller et al., 2015). These challenges can contribute to diabetes-specific emotional distress (Hagger, Hendrieckx, Sturt, Skinner, & Speight, 2016; Weissberg-Benchell & Antisdel-Lomaglio, 2011).

Many youth with T1D experience emotional distress related to the daily burden of living with diabetes (Hagger et al., 2016). Diabetes-specific emotional distress involves negative emotions and fears specific to living with diabetes such as getting upset about out of

range blood glucose values, feeling unsupported by family or friends, or feeling overwhelmed by the diabetes regimen (Fisher et al., 2010; Fisher, Gonzalez, & Polonsky, 2014). Diabetes-specific emotional distress is associated with worse adherence and worse glycemic control (Hagger et al., 2016).

Diabetes distress is not the same construct as depression (Fisher et al., 2014). While over 90% of adults with T1D reporting high levels of depressive symptoms also reported high levels of diabetes-specific emotional distress, when individuals with high depressive symptomatology were evaluated via a structured diagnostic interview, the number of individuals meeting criteria for a diagnosable depressive disorder was significantly lower than what might have been expected based on the self-report depression checklist. The initially high self-reports of depressive symptoms were better accounted for by the emotional distress of managing diabetes (Fisher et al., 2016). Careful consideration of the differences between depression and diabetes-specific emotional distress is important, as the two constructs are independent yet correlated (Boland, Grey, Mezger, & Tamborlane, 1999; Hagger et al., 2016; Weissberg-Benchell & Antisdel-Lomaglio, 2011). Validated measures tapping diabetes-specific distress allow clinicians and researchers to assess the emotional impact of daily diabetes demands and differ from measures of depressed mood or general distress that are independent of contextual precipitants. Differentiating between diabetes distress and depressive symptoms allows for tailored research questions, providing a greater degree of specificity in clinical interventions (Fisher et al., 2014).

Teen diabetes-specific distress is influenced by the family environment and caregivers also may experience distress because of concerns about teen diabetes self-management, conflict about diabetes-related responsibilities, and worries about the future (Hessler, Fisher, Polonsky, & Johnson, 2016; Markowitz et al., 2012). Parent diabetes-specific distress is associated with higher teen hemoglobin A1c (HbA1c) (Rumburg, Lord, Savin, & Jaser, 2017) and is associated with parental and teen depressive symptoms (Whittemore, Jaser, Chao, Jang, & Grey, 2012) and diabetes-specific family conflict (Law, Walsh, Queralt, & Nouwen, 2013).

The Problem Areas in Diabetes Scale (PAID; Polonsky et al., 1995) was developed to assess diabetes-specific distress in adults and has since been adapted for use with youth ages 8–17 years, and their parents (Markowitz et al., 2012; Markowitz, Volkening, Butler, & Laffel, 2015). However, the validation process for this youth-report measure combined children and teens across the developmental spectrum. Adolescence, as compared with childhood, is a time of greater responsibility and associated challenges with diabetes self-care behaviors (Chiang, Kirkman, Laffel, & Peters, 2014). Therefore, measures of distress for teens and their

caregivers that consider unique developmental stressors are needed. The teen version of the PAID, the Problem Areas in Diabetes-Teen version (PAID-T), shows strong preliminary psychometric properties, with evidence of good internal consistency and validity (Weissberg-Benchell & Antisdel-Lomaglio, 2011). A parent of teenager version of the PAID has yet to be validated.

The aims of the current study are to add to the preliminary literature on psychometric properties of the PAID-T, investigate the psychometric properties of the Problem Areas in Diabetes-Parent of Teen version (P-PAID-T, a parent-report measure), reduce the length of the original measures, establish clinical cutoffs, and assess relations with other key psychosocial and medical outcomes. The factor structure of the PAID-T and P-PAID-T may be multifactorial in nature, as earlier measures of diabetes distress have revealed multiple factors in parents of youth with T1D (Hessler et al., 2016; Markowitz et al., 2012) and adults with T1D (Polonsky et al., 2005). For example, the Parent Diabetes Distress Scale for parents of teens revealed four dimensions of distress related to quality of life, teen management distress, parent/teen relationship distress, and health-care team distress (Hessler et al., 2016). The PAID-PR (Parent Revised version) for parents of youth revealed two dimensions, encompassing daily burdens (concrete burden) and worries about the future (unpredictable burden; Markowitz et al., 2012). The Diabetes Distress scale for adults revealed four dimensions comprising emotional burden, health-care provider distress, regimen-specific distress, and interpersonal distress (Polonsky et al., 2005). It is important to note that the two latter measures assess distress for parents of youth across a broad age range and for adults with T1D, and the dimensions for teens and parents of teens are likely to diverge from these other age groups.

The American Diabetes Association recently identified psychosocial variables that should be routinely assessed because of their impact on wellbeing and medical outcomes, one of which was diabetes-specific distress. Other variables included depressive and anxiety symptoms and diabetes-specific family conflict (Young-Hyman et al., 2016). The present study will investigate the relationship between diabetes-specific distress, and these psychosocial concerns, as diabetes-specific distress has been found to be related to emotional (Weissberg-Benchell & Antisdel-Lomaglio, 2011; Whittemore et al., 2012) and familial (Law et al., 2013) problems. In addition, diabetes distress is inversely related to a complementary construct, diabetes resilience-related strengths, or “adaptive processes, behaviors, and attitudes that facilitate achievement of resilient outcomes when faced with [diabetes-related] challenges” (Hilliard, Iturralde, Weissberg-Benchell, & Hood, 2017, p. 2). We hypothesize that the PAID-T and P-PAID-T will demonstrate concurrent validity

with these other measures: specifically, positive associations with HbA1c, blood glucose levels, depressive and anxious symptoms, and diabetes-specific family conflict; and negative associations with diabetes strengths and blood glucose monitoring frequency.

## Method

### Participants

Data are from the Diabetes Camp Matters Study and the Supporting Teen Problem Solving (STePS) study. Methods and inclusion criteria for both studies are published elsewhere (Weissberg-Benchell, Rausch, Iturralde, Jedraszko, & Hood, 2016; Weissberg-Benchell & Rychlik, 2017). For the camp study, data were from youth aged 12 to 18 years, attending one of 42 camps across the United States, and their caregivers. For the STePS study, data were from youth ages 14 to 18 years and their caregivers. Exploratory factor analyses were conducted with the camp data because of its larger sample size and fewer exclusion criteria. Confirmatory analyses were conducted with the STePS data, which also provided other measures for concurrent validity and cutoff scores. Demographics for the two data sets are presented in Table I.

### Procedure

Both studies were conducted in accordance with the ethical principles of the American Psychological Association. For the camp study, camp directors sent e-mails and letters containing the study Weblink to families of youth prior to camp. In total, 1,005 teen and caregiver dyads completed measures online. For the STePS study, recruitment occurred through mailings, clinics, and hospital website postings. Measures were completed online. In contrast to the camp study, participants in the STePS study were excluded during recruitment if they met diagnostic criteria for major depressive disorder, as the purpose of the study was to evaluate the efficacy of a depression prevention program. In total, 260 teen and caregiver dyads completed measures.

### Measures

#### PAID-T and P-PAID-T

The PAID-T (Weissberg-Benchell & Antisdel-Lomaglio, 2011) and P-PAID-T are 26-item measures of diabetes-specific emotional distress in teens with diabetes and their parents. Initial validation and item development procedures are described elsewhere (Weissberg-Benchell & Antisdel-Lomaglio, 2011). Respondents rate how much each item currently applies to them over the past month using a six-point Likert scale (1 = *Not a Problem*, 6 = *Serious Problem*). Higher total scores indicate greater distress. Internal consistency of the 26-item measures was strong for both the camp and STePS studies (PAID-T,  $\alpha_s = .95, .95$ ; P-PAID-T,  $\alpha_s = .95, .96$ , respectively).

### Children's Depression Inventory

The Children's Depression Inventory (CDI) is a 27-item self-report measure of depressive symptoms in youth (Kovacs, 1992). Youth rate each item on a scale from 0 to 2, based on perceived severity over the past 2 weeks. Higher scores indicate greater severity of depressive symptoms. Teens in the STePS study completed the CDI and internal consistency was .87. Although teens in the STePS study were excluded if they had a diagnosis of major depressive disorder or if they met criteria for a depression diagnosis based on a structured clinical interview (Kiddie – Schedule for Affective Disorders and Schizophrenia; Kaufman et al., 1997), there was still a wide range of scores on the CDI ( $M = 7.72$ ,  $SD = 6.17$ , range = 0–29) with about 13% ( $N = 33$ ) reporting higher than average depressive symptoms based on age and gender.

### State–Trait Anxiety Inventory

The State–Trait Anxiety Inventory (STAI) is a 40-item measure of anxiety symptoms; half of the items represent present feelings (state) and half represent feelings in general (trait) (Spielberger, 1983). Items are rated on a four-point Likert scale. Higher scores reflect greater severity of anxiety symptoms. The STAI was rated by teens in the STePS study and had strong internal consistency (state, .93; trait, .93).

### Diabetes Family Conflict Scale

The Diabetes Family Conflict Scale (DFCS) is a 20-item measure of diabetes-specific family conflict (Hood, Butler, Anderson, & Laffel, 2007). DFCS is rated on a three-point Likert scale. Higher scores reflect greater family conflict. Teens and their parents completed DFCS in the STePS study and internal consistency was .91 and .87, respectively.

### Center for Epidemiologic Studies Depression Scale

The Center for Epidemiologic Studies Depression Scale (CES-D) is a 20-item measure of depressive symptoms for adults (Lewinsohn, Seeley, Roberts, & Allen, 1997). The CES-D is rated on a four-point Likert scale. Higher scores reflect greater severity. The CES-D was completed by caregivers in the STePS study and had internal consistency of .87.

### Diabetes Strengths and Resilience Measure for Adolescents

The Diabetes Strengths and Resilience Measure for Adolescents (DSTAR-Teen) is a 12-item measure of diabetes resilience-related strengths as indicated by adaptive behaviors and attitudes about diabetes (Hilliard et al., 2017). It is rated on a five-point Likert scale and higher scores reflect greater strengths. The DSTAR-Teen was completed by teens in the 2015 camp study ( $N = 772$ ) and internal consistency was .77.

**Table I. Participant Characteristics**

Characteristic	Camp Study (N = 1,005) M (SD)	STePS Study (N = 260) M (SD)
Teen age	14.39 (1.52)	15.74 (1.09)
A1c	7.94 (1.56)	9.14 (1.92)
Duration of diabetes (years)	6.98 (3.10)	6.88 (4.03)
Teen gender, % female	<i>n</i> (%) 581 (58)	<i>n</i> (%) 152 (58)
Teen race/ethnicity		
Caucasian	881 (88)	178 (68)
African-American	25 (3)	33 (13)
Hispanic/Latino	39 (4)	26 (10)
Asian	5 (<1)	6 (2)
Other	4 (<1)	17 (7)
Annual family income		
≤\$50,000	204 (20)	39 (15)
\$51–100,000	276 (27)	81 (31)
\$101–175,000	252 (25)	71 (27)
>\$175,000	111 (11)	42 (16)
Insulin administration, % pump	751 (75)	177 (68)
% Regular use of continuous glucose monitor	667 (66)	80 (31)
Living with		
Both parents	733 (73)	191 (73)
Parent and stepparent/partner	105 (10)	19 (7)
One parent	113 (11)	38 (15)
Other	24 (2)	12 (5)
Caregiver relationship to child		
Mother/stepmother/foster mother	896 (89)	232 (89)
Father/stepfather/foster father	88 (9)	20 (8)
Other	13 (1)	3 (1)
Mother education		
6th grade or less	–	1 (<1)
Some middle/high school	16 (2)	9 (3)
High school graduate	70 (7)	22 (8)
Some college	209 (21)	66 (25)
College graduate	433 (43)	109 (42)
Graduate school or professional degree	267 (27)	49 (19)
Father education		
6th grade or less	–	1 (<1)
Some middle/high school	41 (4)	10 (4)
High school graduate	152 (15)	33 (13)
Some college	251 (25)	68 (26)
College graduate	319 (32)	74 (28)
Graduate school or professional degree	214 (21)	59 (23)

### Hemoglobin A1c

HbA1c was used to assess glycemic control. For the STePS study, HbA1c was analyzed at the Diabetes Diagnostic Laboratory, University of Missouri (<http://www.diabetes.missouri.edu>), which served as the reference laboratory for the Diabetes Control and Complications Trial (DCCT) and National Health and Nutrition Examination Survey (NHANES) III and IV. For the camp study, parents reported teens' most recent HbA1c, providing a feasible means to obtain data from youth attending 42 different camps nationwide. While parent report of HbA1c is not the same as the gold standard of objectively measured HbA1c, parent report of teen HbA1c has been used in prior research, supported by a high association between adult self-reported HbA1c and objectively measured HbA1c ( $r = .84$ ) and low missing data or

improbable values (Hessler et al., 2016). In addition, the STePS study included both objectively measured and parent-reported HbA1c, and the correlation was strong ( $r = .84$ ), providing additional support for use of parent-reported HbA1c in the camp study.

### Blood Glucose Checks and Average Blood Glucose

The average number of blood glucose checks per week and average weekly blood glucose levels were obtained from downloads of meters in the STePS study.

### Data Analytic Plan

Analyses were conducted separately for the PAID-T and P-PAID-T. Exploratory factor analysis (EFA) in SPSS version 23 with maximum likelihood extraction and direct oblimin rotation identified factor structures using camp data. Items were removed if they had

**Table II.** Intercorrelations, Ms, and SDs for Study Variables

Measure	1	2	3	4	5	6	7	8	9	10	11	12
1. PAID-T (14-item)	—	.48 <sup>*,a</sup>	.28 <sup>*,a</sup>	-.49 <sup>*,a</sup>								
2. P-PAID-T (15-item)	.44 <sup>*</sup>	—	.36 <sup>*,a</sup>	-.30 <sup>*,a</sup>								
3. HbA1c	.39 <sup>*</sup>	.37 <sup>*</sup>	—	-.22 <sup>*,a</sup>								
4. DSTAR	—	—	—	—								
5. CDI	.64 <sup>*</sup>	.24 <sup>*</sup>	.24 <sup>*</sup>	—	—							
6. STAI (state)	.50 <sup>*</sup>	.28 <sup>*</sup>	.26 <sup>*</sup>	—	.61 <sup>*</sup>	—						
7. STAI (trait)	.59 <sup>*</sup>	.24 <sup>*</sup>	.24 <sup>*</sup>	—	.80 <sup>*</sup>	.76 <sup>*</sup>	—					
8. DFCS (teen)	.36 <sup>*</sup>	.33 <sup>*</sup>	.31 <sup>*</sup>	—	.31 <sup>*</sup>	.25 <sup>*</sup>	.29 <sup>*</sup>	—				
9. DFCS (parent)	.32 <sup>*</sup>	.64 <sup>*</sup>	.29 <sup>*</sup>	—	.14 <sup>*</sup>	.15 <sup>*</sup>	.14 <sup>*</sup>	.34 <sup>*</sup>	—			
10. CES-D	.21 <sup>*</sup>	.54 <sup>*</sup>	.19 <sup>*</sup>	—	.25 <sup>*</sup>	.25 <sup>*</sup>	.24 <sup>*</sup>	.13 <sup>*</sup>	.42 <sup>*</sup>	—		
11. Blood glucose checks	-.17 <sup>*</sup>	-.26 <sup>*</sup>	-.36 <sup>*</sup>	—	-.15 <sup>*</sup>	-.16 <sup>*</sup>	-.18 <sup>*</sup>	-.22 <sup>*</sup>	-.24 <sup>*</sup>	-.17 <sup>*</sup>	—	
12. Average blood glucose	.27 <sup>*</sup>	.29 <sup>*</sup>	.57 <sup>*</sup>	—	.17 <sup>*</sup>	.17 <sup>*</sup>	.16 <sup>*</sup>	.23 <sup>*</sup>	.28 <sup>*</sup>	.11	-.34 <sup>*</sup>	—
M	40.1 <sup>a</sup>	47.7 <sup>a</sup>	7.9 <sup>a</sup>	37.1 <sup>a</sup>	7.7	33.0	37.6	27.7	27.4	8.7	51.9	217.2
	40.3	45.9	9.1									
SD	16.2 <sup>a</sup>	16.0 <sup>a</sup>	1.6 <sup>a</sup>	6.0 <sup>a</sup>	6.2	10.7	10.7	7.2	6.0	7.9	33.0	58.3
	15.9	17.0	1.9									

Note. Intercorrelations from the camp study ( $N=1,005$ ) are presented above the diagonal, and intercorrelations from the STePS study ( $N=260$ ) are presented below the diagonal. CES-D=Center for Epidemiologic Studies Depression scale; CDI=Children's Depression Inventory; DFCS=Diabetes Family Conflict Scale; DSTAR=Diabetes Strengths and Resilience Measure for Adolescents; HbA1c=hemoglobin A1c; PAID-T=Problem Areas in Diabetes-Teen version; P-PAID-T=Problem Areas in Diabetes-Parent of Teen version; STAI=State-Trait Anxiety Inventory.

<sup>a</sup>Camp Study.

\* $p < .05$ .

extreme skewness or kurtosis,  $\geq 50\%$  of participants responded "1=Not a problem," or communalities were  $< .5$ . Parallel analysis ((O'Connor, 2000) identified the number of factors.

Confirmatory factor analysis (CFA) was conducted using the STePS data in LISREL version 8.80 using robust maximum likelihood estimation to adjust for any nonnormality in the data (Satorra & Bentler, 1994). Second-order models with multiple first-order factors were assessed given the conceptual nature of diabetes-specific distress as an overarching construct with multiple dimensions. Acceptable model fit was indicated by root mean square error of approximation (RMSEA,  $\leq .08$ ; Browne & Cudeck, 1992), standardized root mean square residual (SRMR,  $< .08$ ; Hu & Bentler, 1998), nonnormed fit index (NNFI,  $> .90$ ; Marsh, Hau, & Wen, 2004), and comparative fit index (CFI,  $> .90$ ; Marsh et al., 2004).

To identify a severity cutoff on each measure, receiver-operating characteristic (ROC) analyses were used. ROC analyses identify scores that maximize levels of sensitivity and specificity for predicting a dichotomous outcome variable. For our analyses, there was not an available "gold-standard" measure of diabetes-specific distress for teens or caregivers that could be dichotomized and used to identify a cutoff score. Instead, latent profile analysis (LPA) was used to identify two clinically meaningful groups of nondistressed versus distressed teens and caregivers. LPA was conducted using the STePS data in MPlus version 7.3 with full information maximum likelihood estimation, to identify two subgroups of teens with differing levels of HbA1c and emotional symptomatology (depressive symptoms,

anxiety) and two subgroups of caregivers with differing parental depressive symptoms and teen HbA1c levels. Two groups were chosen to facilitate ROC analyses. Goodness-of-fit criteria provided validity for separating participants into two groups, indicated by lower Bayesian information criteria (BIC; Schwarz, 1978) and significant  $p$ -values for both the Lo-Mendell-Rubin test (LMR; Lo, Mendell, & Rubin, 2001) and bootstrap log ratio test (BLRT; McLachlan & Peel, 2000). ROC curves with the STePS data assessed cutoff scores on the PAID-T and P-PAID-T that distinguished between distressed and nondistressed groups of teens and parents. The Youden Index identified cutoff scores at which the sum of sensitivity and specificity was largest.

## Results

A correlation matrix of study variables can be found in Table II.

### PAID-T: Diabetes-Specific Emotional Distress in Teens

#### Exploratory Factor Analysis

EFA with oblique rotation was used to analyze the factor structure of the 26 items using the camp study data ( $N=1,005$ ). None of the items had extreme skewness or kurtosis and none had  $\geq 50\%$  participants who responded "1=Not a problem." The Kaiser-Meyer-Olkin (KMO) test = .96 and Bartlett's test,  $\chi^2(325) = 16,117.60$ ,  $p < .001$ , indicated an analyzable correlation matrix. Parallel analysis suggested three factors.

Follow-up of the three-factor solution identified factors representing *emotional burden, family and*

*friends distress*, and *regimen-specific distress*. Eleven items with communalities  $<.5$  were removed one at a time. One item loaded moderately on a factor with poor conceptual fit and was therefore removed (“Fitting my diabetes regimen into my day when I’m away from home [e.g. school, work, etc.]” loaded on the *emotional burden* factor), resulting in a final 14-item scale. Three factors accounted for 64.3% of the variance in the 14 items (rotation sums of squared loadings: *emotional burden* = 5.63; *family and friends distress* = 5.90; *regimen-specific distress* = 4.29). The three factors were moderately to strongly correlated (*emotional burden* and *family and friends distress*,  $r = .66$ ; *emotional burden* and *regimen-specific distress*,  $r = .47$ ; and *family and friends distress* and *regimen-specific distress*,  $r = .54$ ). Factor loadings for the *emotional burden* factor ranged from .93 (“Feeling sad when I think about having and living with diabetes.”) to .49, for the *family and friends distress* factor from .90 (“Feeling like my parents don’t trust me to care for my diabetes.”) to .51, and for the *regimen-specific distress* factor from .85 (“Feeling that I am not checking my blood sugars often enough.”) to .49.

### Confirmatory Factor Analysis

CFA assessed the fit of a second-order model with three first-order factors for the 14-item PAID-T scale using the STePS data ( $N=260$ ). The second-order model with three first-order factors provided acceptable fit, SRMR = .06, NNFI = .97, CFI = .98, RMSEA = .08. The variance explained in each item ranged from 47.5% (“Worrying that diabetes gets in the way of having fun and being with my friends.”) to 74.0% (“Feeling that I am often failing with my diabetes regimen.”). First-order standardized factor loadings for the *emotional burden* factor ranged from .69 to .83, for the *family and friends distress* factor from .71 to .84, and for the *regimen-specific distress* factor from .75 to .86. Standardized loadings for each first-order factor on the second-order *diabetes-specific distress* factor ranged from .78 (*regimen-specific distress*) to .88 (*emotional burden*). First-order factors were moderately to strongly correlated (*emotional burden* and *family and friends distress*,  $r = .69$ ; *emotional burden* and *regimen-specific distress*,  $r = .74$ ; and *family and friends distress* and *regimen-specific distress*,  $r = .65$ ). The variance explained in each first-order factor ranged from 61.2% (*family and friends distress*) to 78.1% (*emotional burden*). As a competing model to the higher-order model with three first-order factors, a one-factor model was assessed with CFA using the STePS data. The one-factor model did not provide acceptable fit (SRMR = .09, NNFI = .89, CFI = .91, RMSEA = .19).

The total score for this scale showed strong reliability for the camp and STePS data, 14 items, Cronbach’s

$\alpha$ s = .93 and .93; and three factors of *emotional burden*, five items,  $\alpha$ s = .89, .87; *family and friends distress*, five items,  $\alpha$ s = .89, .89; and *regimen-specific distress*, four items,  $\alpha$ s = .85, .88, respectively).

### Concurrent Validity of the 14-Item PAID-T

See Table II for correlations between distress and psychosocial and medical variables. Females reported significantly greater distress than males in both the camp, Cohen’s  $d = 0.32$ ,  $t(993) = 5.00$ ,  $p < .001$ , and STePS studies,  $d = 0.45$ ,  $t(258) = 3.47$ ,  $p < .001$ . Distress was not correlated with age,  $r = .00$ ,  $p = .989$ , or years since diagnosis,  $r = -.03$ ,  $p = .634$ , in the STePS study, but was correlated in the camp study, such that older teens,  $r = .09$ ,  $p = .009$ , who have had diabetes for longer,  $r = .08$ ,  $p = .015$ , were more likely to rate greater distress than their younger peers who have had fewer years since diagnosis. Teen distress was associated with family income in the camp dataset,  $F(3, 839) = 14.79$ ,  $p < .001$ , such that distress was higher for income  $\leq \$50,000$  compared with  $> \$50,000$  ( $\$51-100$ ,  $d = 0.37$ ,  $p < .001$ ;  $\$101-175$ ,  $d = 0.47$ ,  $p < .001$ ;  $> \$175$ ,  $d = 0.71$ ,  $p < .001$ ), and was lower for income  $> \$175,000$  compared with income  $\leq \$100,000$  ( $\$51-100$ ,  $d = 0.33$ ,  $p = .026$ ). Distress was not associated with income in the STePS dataset,  $F(3, 227) = .875$ ,  $p = .455$ , or race/ethnicity [camp,  $F(4, 949) = 1.36$ ,  $p = .245$ ; STePS,  $F(5, 254) = 1.47$ ,  $p = .200$ ].

### Severity Cutoff and Clinical Utility

A severity cutoff score on the PAID-T was identified using an ROC curve. Subgroups of participants were first identified using LPA, which was set to extract two groups based on differing HbA1c, depressive symptoms, and state and trait anxiety. The two class model (entropy = 0.89; BIC = 6,398.58; LMR = 372.46,  $p < .001$ ; BLRT = -3,355.98,  $p < .001$ ) fit significantly better than one class (BIC = 6,727.97). One subgroup ( $N = 172$ ) was composed of teens with lower HbA1c ( $M = 8.73$ ,  $SE = 0.13$ ), depressive symptoms ( $M = 4.53$ ,  $SE = 0.30$ ), and anxiety (state,  $M = 27.45$ ,  $SE = 0.48$ ; trait,  $M = 31.49$ ,  $SE = 0.58$ ), and the other group ( $N = 88$ ) was composed of teens with higher HbA1c ( $M = 9.95$ ,  $SE = 0.23$ ), depressive symptoms ( $M = 14.00$ ,  $SE = 0.69$ ), and anxiety (state,  $M = 43.99$ ,  $SE = 1.28$ ; trait,  $M = 49.56$ ,  $SE = 0.90$ ). There were no differences between groups based on gender,  $\chi^2(1, N = 263) = 2.76$ ,  $p = .096$ , race/ethnicity,  $\chi^2(5, N = 263) = 4.49$ ,  $p = .482$ , family income,  $\chi^2(3, N = 233) = 4.42$ ,  $p = .220$ , age,  $t(261) = -.92$ ,  $p = .358$ , or years since diagnosis,  $t(261) = .97$ ,  $p = .334$ . The subgroup with greater negative emotions and higher HbA1c reported more diabetes distress,  $t(258) = -9.77$ ,  $p < .001$ .

The ROC curve assessing the sensitivity and specificity of the PAID-T for identifying group membership showed good discriminability with an area under the curve of .82. Distress on the PAID-T was determined to be a score of  $\geq 44$ , as this score maximized the combined sensitivity (PAID-T score 43.5 = .76) and specificity (PAID-T score 43.5 = .77) for differentiating teens with greater HbA1c and more negative emotional symptoms.

#### P-PAID-T: Diabetes-Specific Emotional Distress in Parents of Teens

##### Exploratory Factor Analysis

Initial analyses indicated that two items from the 26-item scale should be removed from subsequent analyses because  $\geq 50\%$  of participants responded “1 = Not a problem.” EFA with oblique rotation was used to analyze the factor structure of the remaining 24 items. KMO = .96 and Bartlett’s test,  $\chi^2(253) = 14,258.14$ ,  $p < .001$ , indicated an analyzable correlation matrix. Parallel analysis indicated two factors.

Follow-up of the two-factor solution indicated factors representing *emotional burden* and *regimen-specific distress*. Nine items with communalities  $< .5$  were removed one at a time, resulting in a final 15-item scale. Two factors accounted for 58.62% of the variance in the 15 items (rotation sums of squared loadings: *emotional burden* = 6.27; *regimen-specific distress* = 6.00). The two factors were moderately correlated ( $r = .56$ ). Factor loadings for the *emotional burden* factor ranged from .84 (“Feeling sad when I think about my child having and living with diabetes.”) to .43 and for the *regimen-specific distress* factor from .92 (“Feeling that my child does not check blood sugars often enough.”) to .52.

##### Confirmatory Factor Analysis

CFA was used to assess the fit of a second-order model with two first-order factors for the 15-item P-PAID-T scale using the STePS data. The second-order model with two first-order factors did not provide adequate fit, SRMR = .07, NNFI = .96, CFI = .97, RMSEA = .11. A competing one-factor model also did not provide adequate fit, SRMR = .08, NNFI = .93, CFI = .94, RMSEA = .15.

Whereas one prior measure of parent-reported diabetes-specific distress found two dimensions of distress (Markowitz et al., 2012), a different measure found four dimensions of distress for parents of teens (Hessler et al., 2016). Therefore, the present study assessed whether a second-order model with four first-order factors could instead provide adequate fit for the data. A four-factor model was first identified using EFA with the camp study data of the 15-item P-PAID-T scale. The four-factor model with EFA appeared to separate *regimen-specific distress* into *personal*

*regimen-specific distress* and *child regimen-specific distress* and to separate the *emotional burden* factor into *negative emotions* and *keeping up with chronic demands* factors. Fit was adequate for the second-order model with four first-order factors, SRMR = .06, NNFI = .98, CFI = .98, and RMSEA = .08. The variance explained in each of the observed variables ranged from 41.8% (“Feeling angry when I think about my child having and living with diabetes.”) to 84.4% (“Worrying that my child will miss or skip blood sugar checks.”). First-order standardized factor loadings for the *negative emotions* factor ranged from .65 to .80, the *keeping up with chronic demands* factor from .88 to .89, the *child regimen-specific distress* factor from .83 to .92, and *personal regimen-specific distress* factor from .78 to .85. Standardized loadings for each first-order factor on the second-order *diabetes-specific distress* factor ranged from .85 (*child regimen-specific distress*) to .94 (*personal regimen-specific distress*). First-order factors were strongly correlated and ranged from .76 (*child regimen-specific distress* and *keeping up with chronic demands* factors) to .85 (*personal regimen-specific distress* and *keeping up with chronic demands* factors). The variance explained in each first-order factor ranged from 72.5% (*child regimen-specific distress*) to 89.6% (*personal regimen-specific distress*).

The total score for this scale showed strong reliability for the camp and STePS studies, 15 items, Cronbach’s  $\alpha$ s = .94 and .95, and the four factors (*personal regimen-specific distress*, three items,  $\alpha$ s = .83, .85; *child regimen-specific distress*, four items,  $\alpha$ s = .87, .92; *keeping up with chronic demands*, two items,  $\alpha$ s = .81, .87; and *negative emotions*, six items,  $\alpha$ s = .88, .88, respectively).

##### Concurrent Validity of the 15-Item P-PAID-T

Parent distress as measured by the 15-item P-PAID-T was positively correlated with teen-reported distress as measured by the 14-item PAID-T. See Table II for correlations between distress and psychosocial and medical variables. There was a significant overall difference in distress based on teen race/ethnicity in the camp,  $F(4, 949) = 3.05$ ,  $p = .016$ , and STePS studies,  $F(5, 250) = 2.41$ ,  $p = .037$ ; however, post hoc analyses did not indicate any significant pairwise comparisons. Parent distress was associated with family income in the camp dataset,  $F(3, 839) = 13.12$ ,  $p < .001$ , such that distress was higher for income  $\leq \$50,000$  compared with income  $> \$50,000$  ( $\$51\text{--}100$ , Cohen’s  $d = 0.36$ ,  $p < .001$ ,  $d = 0.52$ ,  $p < .001$ ;  $> \$175$ ,  $d = 0.60$ ,  $p < .001$ ). Distress was also associated with income in the STePS study,  $F(3, 229) = 3.23$ ,  $p = .023$ , such that distress was higher for income  $\leq \$50,000$  compared with  $> \$175,000$  ( $d = .71$ ,  $p = .016$ ). Parent distress was not correlated with teen

age (camp,  $r = -.03$ ,  $p = .370$ ; STePS,  $r = -.09$ ,  $p = .156$ ) or years since diagnosis (camp,  $r = -.03$ ,  $p = .409$ ; STePS,  $r = -.06$ ,  $p = .309$ ).

### Severity Cutoff and Clinical Utility

To determine a cutoff score on the P-PAID-T, LPA first identified two subgroups of caregivers with differing levels of caregiver depressive symptoms and teen HbA1c. The two class model (entropy = 0.90; BIC = 2,826.42; LMR = 81.76,  $p = .024$ ; BLRT = -1,437.03,  $p < .001$ ) fit significantly better than one class (BIC = 2,896.35). One subgroup ( $N = 235$ ) was composed of caregivers with fewer depressive symptoms ( $M = 6.52$ ,  $SE = 0.51$ ) and teen HbA1c ( $M = 9.05$ ,  $SE = 0.13$ ), and a smaller subgroup ( $N = 28$ ) was composed of caregivers with greater depressive symptoms ( $M = 25.77$ ,  $SE = 2.91$ ) and teen HbA1c ( $M = 9.84$ ,  $SE = 0.49$ ). There were no differences between groups based on parent relationship to child,  $\chi^2(1, N = 255) = 3.98$ ,  $p = .263$ , teen gender,  $\chi^2(1, N = 263) = .09$ ,  $p = .771$ , teen ethnicity,  $\chi^2(5, N = 263) = 2.79$ ,  $p = .733$ , family income,  $\chi^2(3, N = 233) = 3.14$ ,  $p = .371$ , teen age,  $t(261) = 1.29$ ,  $p = .198$ , or years since diagnosis,  $t(261) = .90$ ,  $p = .367$ . The subgroup with greater depressive symptoms and teen HbA1c reported greater diabetes distress,  $t(254) = -6.38$ ,  $p < .001$ .

The ROC had good discriminability between groups with an area under the curve of .82. The distress cutoff score on the P-PAID-T was determined to be 54, which maximized the combined sensitivity (P-PAID-T score 53.5 = .82) and specificity (P-PAID-T score 53.5 = .75) for distinguishing between groups.

### Discussion

The present analysis investigated the psychometric properties of two complementary diabetes-specific distress measures—the PAID-T and P-PAID-T. Exploratory and confirmatory factor analyses were used to validate the structures of these measures using two large, national samples of teens with T1D and their parents. Internal consistency of the 14-item PAID-T (Cronbach's  $\alpha_s = .93$  and  $.93$ ) and 15-item P-PAID-T (Cronbach's  $\alpha_s = .94$  and  $.95$ ) was excellent, and reliability was strong for all factors ( $\alpha_s = .81$ – $.92$ ).

Multidimensional facets of diabetes-specific emotional distress for teens included emotional burden, regimen-specific distress, and family and friends distress factors, similar to diabetes-specific distress among adults (Polonsky et al., 2005). For teens, diabetes-specific distress involves three dimensions that include negative emotions such as sadness and anger about having diabetes, the practical experience of the chronic and demanding nature of diabetes tasks,

and the perception of feeling unsupported by family and friends. These sources of distress are consistent with research on stressors for teens with T1D that include stress specific to diabetes regimen demands and relationships with family and friends (Davidson et al., 2004).

For the parent measure of diabetes-specific distress, EFA of the larger, nationally representative sample identified a two-factor structure comprised of emotional burden and regimen-specific distress. In contrast, CFA of the STePS data, a less representative sample with greater exclusion criteria and a narrower age range, identified a four-factor structure of diabetes-specific distress comprised of personal regimen-specific distress, child regimen-specific distress, keeping up with chronic demands, and negative emotions. Given these sample differences and the discrepancy between factor structures, no conclusions about a clear factor structure can be made at this time. For the purposes of research and clinical care, it is most useful to interpret this instrument using a summed total score, as supported by a second-order factor structure and high correlations between factors. More data are needed from nationally representative populations to test and cross-validate the factor structures identified in the present research and to further investigate dimensions of diabetes-specific distress for parents of teens.

Based on the two proposed factor-structures for parents, there are a few notable similarities and differences between parent and teen diabetes-specific distress. Teens and parents show some similarities in the facets comprising distress, including negative emotions about diabetes and the demanding diabetes regimen. However, neither of the proposed factor structures for parents shows distress from their interpersonal context as found for teens. It may be that the heightened importance of peer relationships during adolescence (Steinberg, 2014), and the importance of parental support in diabetes management for teens (Markowitz, Garvey, & Laffel, 2015) makes the environmental context an especially key contributing factor to teen distress. As future research continues to investigate the factor structure of parent diabetes-specific distress, more clarity regarding differences and similarities between parent and teen distress may emerge.

Distress intensity varied based on demographic variables. Girls were more likely to rate higher distress than boys, consistent with prior studies (LaSaite, Ostrauskas, Zalinkevicius, Jurgevicene, & Radzevicene, 2016). Parental and teen distress were higher for families with lower annual income, indicating that financial stressors may contribute to greater diabetes-specific distress. While age of teens and years since diagnosis had a small positive association with distress in the camp dataset, which included participants age  $\geq 12$  years, the STePS



data set with participants  $\geq 14$  years did not show an association. It may be that distress increases for teens as they enter high school and remains consistently high after around age 14 years. Race/ethnicity was not associated with parent or teen distress.

Diabetes-specific emotional distress was correlated in the expected direction with psychosocial and health-related outcomes. As hypothesized, distress among both teens and parents positively correlated with HbA1c, average blood glucose, family conflict, teen-reported state and trait anxiety, and teen depressive symptoms; and negatively correlated with blood glucose checks per week and teen diabetes strengths. Additionally, parent distress was positively correlated with parent depressive symptoms. The small to moderate associations are similar to those previously published about adolescents with T1D (Hilliard et al., 2017; Jaser, Linsky, & Grey, 2014; Jaser, Patel, Xu, Tamborlane, & Grey, 2017; Law et al., 2013). In contrast to the present findings, Jaser and colleagues (Jaser et al., 2014) did not find associations between parent distress and HbA1c or parent distress and teen depression, but found a similar, small association between parent distress and family conflict and parent distress and parent depressive symptoms.

The magnitude of correlations between distress and other constructs revealed interesting patterns. First, correlations between diabetes-specific distress and glycemic control for parents and teens were similar in both studies, supporting findings of moderate correlations. Second, distress was only moderately correlated with depressive symptoms and anxiety, indicating that, while related, distress is not a redundant construct. Third, the association between parent distress and teen anxiety ( $r = .24$  for state;  $.28$  for trait) was smaller than between teen distress and teen anxiety ( $r = .50$  for state;  $.59$  for trait), with a similar pattern for parent and teen depressive symptoms. These findings suggest that teen distress is not strongly influenced by parent distress or depressive symptoms, and vice versa, given the low cross-respondent correlations. Fourth, whereas teen-reported distress had small associations with both teen- and parent-reported diabetes-specific family conflict, parent distress was moderately correlated with parent report of family conflict, suggesting that family conflict for parents may have a stronger role in contributing to, or being affected by, diabetes-specific distress. These findings may guide future research on associations between parent and teen distress and other key psychosocial outcomes.

#### Clinical Utility of the PAID-T and P-PAID-T

The clinical utility of the PAID-T and P-PAID-T was investigated by assessing each measure's accuracy in identifying clinically meaningful subgroups of teens and parents. Two empirically derived subgroups of

teens were identified with differing levels of depressive symptoms, state and trait anxiety, and HbA1c. The less distressed group had ratings of emotional distress in the nonclinically significant range and HbA1c below the national mean for teens though still above the target level of 7.5% (Miller et al., 2015). In contrast, the more distressed group rated depressive symptoms at or approaching elevated levels (Kovacs, 1992), state and trait anxiety at elevated levels (Spielberger, 1983), and HbA1c above the national mean and even higher than recommended compared with the less distressed group (Miller et al., 2015). For caregivers, the less distressed group rated their depressive symptoms in the nonclinically significant range and teen HbA1c at the national mean for teens, though still higher than the target level. In contrast, the more distressed group rated depressive symptoms above the cutoff for sub-clinical depression (Lewinsohn et al., 1997) and HbA1c above the national mean and even higher than recommended compared with the less distressed group (Miller et al., 2015). Using ROC curves, the PAID-T and P-PAID-T adequately distinguished between groups, and a cutoff score was identified at 44 for the PAID-T and 54 for the P-PAID-T, at which the combined sensitivity and specificity for distinguishing between groups was maximized.

#### Limitations

There are limitations of the present study that should be addressed in future research. First, the factor structure suggested by the EFA for parents in the camp study differed from that indicated by the CFA with the STePS study. It is possible that the additional two factors added to improve fit in the CFA analysis to acceptable levels were an artifact of the STePS data set. Thus, cross-validation with additional samples should be used to assess the two-factor and four-factor structures identified in the present study for the P-PAID-T.

Second, ROC curves are often used to assess the accuracy of a new measure in predicting the binary outcome of an existing "gold-standard" measure. There is no current gold standard measure of diabetes-specific emotional distress for teenagers or their parents that could be used to assess the construct validity of the PAID-T and P-PAID-T with ROC curves. Future research may address this limitation with data from clinical interviews on diabetes distress for teens and their parents, to assess measure accuracy and confirm the present study's distress cutoff scores.

An important limitation of the present study is that STePS participants were excluded if they had clinical depression. This exclusion limits generalizability of CFA and ROC curve findings to teens who do not meet criteria for major depressive disorder and their parents. Cutoff scores identified in the current sample

may only differentiate distressed from nondistressed teens who do not meet criteria for major depressive disorder but may not generalize to samples with clinical depression who are more likely to have higher levels of diabetes-specific distress (Hagger et al., 2016). Despite the limitations of the present sample, the severity cutoff scores identified in the present study have been found to be useful for differentiating clinically meaningful subgroups of teens and their parents, and further research is needed on depressed teens and their parents to confirm the generalizability of the present findings.

Additionally, the only type of negative emotional symptom assessed in the present study for caregivers was depressive symptoms. As other types of emotional symptoms (i.e., anxiety) were not assessed for caregivers as they were for teens, the cutoff score identified on the P-PAID-T may not identify some caregivers who report other types of emotional symptoms.

## Conclusions

The present study provides additional support for the PAID-T and P-PAID-T as valid, reliable, and clinically useful instruments for identifying diabetes-related distress among teenagers with T1D and their parents. This study builds on prior research assessing the validity of diabetes-specific distress measures among teens, youth in general, parents, and adults with T1D (Hessler et al., 2016; Markowitz et al., 2012, 2015; Polonsky, et al., 1995; Weissberg-Benchell & Antisdel-Lomaglio, 2011). Findings suggest that these measures may be helpful for identifying teens and parents who would benefit from interventions to reduce distress, potentially ameliorate associated feelings of depression and anxiety, and improve glycemic control during a developmental stage when support in these areas is greatly needed.

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