

# Psychometric Properties of the Parent and Child Problem Areas in Diabetes Measures

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## Abstract

**Objective** Children with type 1 diabetes and their parents face daily self-care demands, leading to diabetes-specific emotional distress. A standardized measure of diabetes distress can guide clinical care and prevent negative outcomes. **Methods** This study evaluated the psychometric properties of child- and parent-report measures of the Problem Areas in Diabetes Scale, adapted for children ages 8–12 (PAID-C) and their parents (P-PAID-C). Participants were from 42 diabetes camps in the United States. Children ( $N = 804$ ; mean age =  $10.3 \pm 1.1$ ) and parents ( $N = 968$ ) completed measures of diabetes distress, diabetes-related strengths, and self-care skills. Half of the sample was used for exploratory factor analyses (EFA) with direct oblimin rotation and the other half for confirmatory factor analyses (CFAs). **Results** For the PAID-C, EFA and CFAs supported an 11-item two-factor measure, Cronbach's  $\alpha = .91$ , accounting for 54.6% of the variance. For the P-PAID-C, analyses resulted in a 16-item measure, Cronbach's  $\alpha = .92$ , accounting for 51.9% of the variance. PAID-C and P-PAID-C scores were positively correlated with HbA1c ( $r_{\text{child}} = .08, p = .04$ ;  $r_{\text{parent}} = .18, p < .001$ ), and negatively correlated with diabetes-related strengths ( $r_{\text{child}} = -.38, p < .001$ ,  $r_{\text{parent}} = -.29, p < .001$ ) and parent report of child self-care skills ( $r_{\text{parent}} = -.13, p < .001$ ;  $r_{\text{child}} = -0.07, p = \text{ns}$ ). **Conclusions** Initial psychometrics suggest that the PAID-C and P-PAID-C reliably and validly capture diabetes-specific emotional distress for children and their parents. Associations with glycemic control, self-care, and diabetes strengths demonstrate criterion validity. Both measures have potential applications for routine, clinic-based assessments of diabetes distress and may guide clinical decision-making.

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

## Introduction

Children with type 1 diabetes (T1D) are at increased risk for psychological burdens (Hilliard, Herzer, Dolan, & Hood, 2011; Yi-Frazier et al., 2015), and may experience difficulties with diabetes management

and worsening glycemic control, particularly when they reach adolescence (Miller et al., 2015). Diabetes-specific distress has been linked with suboptimal diabetes self-management and glycemic outcomes in

adolescence (Shapiro et al., 2017). Screening for diabetes-specific distress earlier in childhood could facilitate early detection and interventions to reduce distress and prevent worsening distress, diabetes burnout, depressive symptoms, and subsequent mismanagement of diabetes care (Bernstein, Stockwell, Gallagher, Rosenthal, & Soren, 2013; Hilliard, Herzer, Dolan, & Hood, 2011; Jaser et al., 2012).

Parents of children with T1D experience stressors unique to caring for a child with diabetes, including managing the daily regimen demands, diabetes-related family conflict, and worrying about short- and long-term medical complications (Patton, Dolan, Smith, Thomas, & Powers, 2011; Sweenie, Mackey, & Streisand, 2014). Approximately 20–30% of parents of children with T1D experience clinically significant levels of depressive symptoms and anxiety (Jaser, Whittemore, Ambrosino, Lindemann, & Grey, 2007; Wiebe et al., 2011). Stress related to caring for a child with T1D is associated with lower parent perceived efficacy and engagement in diabetes management tasks (Streisand, Swift, Wickmark, Chen, & Holmes, 2005), higher parental fear of hypoglycemia, increased depressive symptoms among parents and children (Patton et al., 2011), and worse glycemic control.

Many studies on diabetes distress have not used a diabetes-specific measure of emotional distress in children and their parents; rather, measures of general distress are often used as proxies, including measures of general psychological functioning (Wiebe et al., 2011), and depressive symptoms (Jaser, Patel, Xu, Tamborlane, & Grey, 2017). While these general measures of distress are helpful constructs, there are specific stressors related to living with diabetes (e.g., feeling nagged to complete diabetes self-management tasks, discomfort associated with hyper- and hypoglycemic events, self-consciousness about visibility of diabetes management devices/tasks) that these measures do not capture. Assessment of diabetes-specific stressors, rather than general stressors, is valuable because it can increase specificity in research and clinical encounters.

The Problem Area in Diabetes (PAID) is a widely used measure of diabetes-specific emotional distress in adults (Polonsky et al., 1995; Welch, Jacobson, & Polonsky, 1997), which has been adapted for use with adolescents and their parents (Markowitz, Volkening, Butler, & Laffel, 2015; Markowitz et al., 2012; Weissberg-Benchell & Antisdel-Lomaglio, 2011). The PAID teen version (PAID-T) and parent of teen version (P-PAID-T, Shapiro et al., 2017) are valid and reliable measures for use with adolescents and their parents. The PAID-T has a three-factor structure of diabetes distress including the negative emotions related to having diabetes (emotional burden), the day-to-day burden of managing diabetes tasks (regimen-specific

distress), and the perception that one's family or friends are unsupportive with regard to diabetes management (family and friends distress). For the P-PAID-T, no conclusions were made about a clear factor structure; therefore, it is recommended that a summed total score is used to interpret the measure (Shapiro et al., 2017). Given marked developmental differences between elementary-aged children and adolescents, the aim of this study was to adapt and validate a separate PAID measure for use with children with T1D (ages 8–12) and their parents. It was hypothesized that the child version (PAID-C) and the parent version (P-PAID-C) would be multidimensional, similar to the adolescent measures (Shapiro et al., 2017) though likely showing unique factor structures given developmental differences between the two age groups, and would demonstrate strong reliability and validity. A brief standardized measure of diabetes-specific emotional distress in children with T1D and their parents could guide clinical care through early identification of distress and intervention to prevent negative medical and psychosocial outcomes.

## Methods

Study procedures were approved by the Institutional Review Board (IRB) at Ann & Robert H. Lurie Children's Hospital of Chicago.

### Survey Development

All 26 items from the original Problem Areas in Diabetes-Teen (PAID-T) and Parent (P-PAID-T) versions (Weissberg-Benchell & Antisdel-Lomaglio, 2011; Weissberg-Benchell, Hood, & Antisdel-Lomaglio, 2014) were used to create the initial draft of the PAID-C (child version) and P-PAID-C (parents of children version) to ensure items relevant for younger youth were not prematurely excluded. Three pediatric psychologists reviewed the content, language, and format of the questionnaire to ensure that it was developmentally appropriate for younger children. Through this process, the language was simplified to improve readability and comprehension for younger children; however, the content of each item was retained. For example, the teen item, "worrying about the future and the possibility of serious complications," was changed to "worrying about my future and the chance of getting sick." The P-PAID-C was left unchanged from the original P-PAID-T. Consistent with the original adult-report PAID and the teen versions, the PAID-C and P-PAID-C are scored using a 6-point Likert scale (1 = *Not a Problem*, 6 = *Big/Serious Problem*). Responses target how much each diabetes-related experience bothers/upsets the individual respondent over the past month. Items are summed to create an overall distress score,

with higher scores indicating greater emotional distress.

### Participants

Participants were recruited from 42 diabetes camps, representing 106 camp sessions, throughout the United States, during the summers of 2014 and 2015 as part of a larger study (Weissberg-Benchell & Rychlik, 2017). All campers between 8 and 18 years old with a parent able to consent and complete the study questionnaires in English were eligible to participate. It was not a requirement for the parent or caregiver to be primary caregiver in order to participate. Camp directors sent e-mails and/or letters to families enrolled in camp, inviting them to learn more about participating via the participant information sheet on the study website. Parents interested in the study provided consent and children provided assent electronically. The parents and campers could choose to have the study questionnaires sent to either the parent's email only, or to the parent's email and the camper's email address. Four weeks prior to the camp session, a link containing the participant-specific questionnaires (separate for child and parent) was emailed to consenting families. Participants could complete the questionnaires via a secure, Health Insurance Portability and Accountability Act (HIPAA)-compliant online survey portal up until the child's arrival to camp. Parents who consented, but did not complete the surveys prior to camp starting, were sent an email reminder to complete the surveys within the first week. Families received postcamp surveys 2 weeks after camp ended. Those who did not complete the postcamp surveys were sent an email reminder to complete the surveys 1 week later. As incentive for participation, families were invited to participate in a raffle to win a \$200 gift card after completing the precamp surveys and again after completing the postcamp surveys.

For the present study, data from campers ages 8–11.9 years ( $N = 804$ ,  $M = 10.3$ ,  $SD = 1.1$  years) and parents of children in the same age range ( $N = 968$ ) were analyzed. To be included in the current study, children needed to have a diabetes duration  $>1$  year, the ability to read and speak English, and have no other major medical or psychiatric diagnoses. See Table 1 for sample demographics.

### Procedure

Children completed the PAID-C (see description above), the Diabetes Strengths and Resilience measure (DSTAR), and the Diabetes Skills Checklist-Child version. Parents completed the P-PAID-C (see description above) and the Diabetes Skills Checklist-Parent version. Hemoglobin A1c was collected via parent report of the child's most recent value.

**Table 1.** Demographic Characteristics

	Children ( $N = 804$ )	
	Mean	$SD$
Age	10.3	1.1
A1c	7.6	1.2
	$n$	%
Gender: female	520	51.6
Racial identity		
White/non-Hispanic	837	83.1
Black/non-Hispanic	32	3.2
Hispanic/Latino	51	5.1
Other race/ethnicity	12	1.2
Use insulin pump	722	71.7
Use pens	193	19.2
Use syringes	50	5.0
	Parents/caregivers ( $N = 968$ )	
Relationship to child	$n$	%
Mother	831	82.5
Father	77	7.6
Grandparent	4	0.4
Guardian	3	0.3
Annual income		
$< \$25,000$	68	6.8
$\$26,000$ – $50,000$	134	13.3
$\$51,000$ – $75,000$	131	13.0
$\$76,000$ – $100,000$	156	15.5
$\$101,000$ – $125,000$	116	11.5
$\$126,000$ – $150,000$	73	7.2
$\$151,000$ – $175,000$	62	6.2
$> \$175,000$	127	12.6
Unknown	100	9.9
Maternal education		
Less than high school	14	1.4
High school graduate	58	5.8
Some college	204	20.3
College graduate	417	41.4
Graduate/professional degree	272	27.0
Paternal education		
Less than high school	36	3.6
High school graduate	139	13.8
Some college	221	21.9
College graduate	292	29.0
Graduate/professional degree	253	25.1

The DSTAR is a 12-item youth self-report measure that assesses perceived competence in managing daily diabetes tasks and adapting to the unpredictability of diabetes, as well as perceived support from others around diabetes (Hilliard, Iturralde, Weissberg-Benchell, & Hood, 2017; Hilliard, Kushner, Hood, Weissberg-Benchell, & Anderson, 2015). The DSTAR is scored using a 5-point Likert scale (0 = *Never*, 4 = *Almost Always*). Items are positively worded and refer to youths' perceived strengths related to diabetes (e.g., "I am good at taking care of high or low blood sugars"). Items are summed and higher scores indicate a greater number of strengths.

The Diabetes Skills Checklist-Child (Evans, Davis, & Weissberg-Benchell, 2016) is a 23-item self-report measure that assesses perceived independence in diabetes self-care skills, such as treating high- and

low-blood sugars, counting carbohydrates, managing diabetes during exercise, and managing diabetes technology. The Diabetes Skills Checklist is scored using a 3-point Likert scale (1 = *Disagree*, 3 = *Not Sure*, 5 = *Agree*). All items are summed to create a total score, where higher scores reflect higher perceived independence in diabetes skills. The Diabetes Skills Checklist-Parent consists of the same content as the child version, but reflects parent perceptions regarding their child's independence in self-care skills. It is scored using a 5-point Likert scale (1 = *Strongly Disagree*, 5 = *Strongly Agree*; higher scores indicate higher perceived independence).

### Data Analysis Plan

The sample was split randomly to use half of the sample for exploratory factor analyses (EFA, Sample 1,  $N = 504$ ) and the other half for confirmatory factor analysis (CFA, Sample 2,  $N = 503$ ). Using Sample 1, preliminary analyses identified items for deletion in which there was extreme skewness or kurtosis, or in which >50% of respondents reported floor ("Not a Problem") or ceiling ("Always a Problem") effects. Item-to-total correlations were conducted on remaining items for the PAID-C and P-PAID-C and item-to-total correlations that were <0.4 were deleted. The remaining items for each measure were subjected to EFA using maximum likelihood extraction and direct oblimin rotation. Kaiser–Meyer–Olkin (KMO) greater than 0.6 and a significant value for Bartlett's Test of Sphericity were utilized to detect an analyzable correlation matrix. Parallel analysis (O'Connor, 2000) was used to identify the number of factors to retain. Items with communalities <0.4 were deleted. Reliability analysis using Cronbach's  $\alpha$  was conducted on remaining items to assess internal consistency of the total score and each factor. Using Sample 2, CFA was conducted in MPlus version 8 with robust maximum likelihood estimation (Muthén & Muthén, 2017). Fit indices of RMSEA  $\leq 0.08$  (Browne & Cudeck, 1992), SRMR  $\leq 0.08$  (Hu & Bentler, 1998), NNFI  $\geq 0.90$  (Marsh, Hau, & Wen, 2004), and CFI  $\geq 0.90$  (Marsh et al., 2004) were used to determine adequate model fit.

Using the combined total sample, correlations between the total score of each measure and HbA1c, self-care skills, and diabetes strengths assessed criterion validity. Differences in distress scores based on demographic variables including age, child gender, racial identity, insulin delivery method (pump, multiple daily injections), caregiver education level, and family income were analyzed via correlations, independent samples  $t$ -tests, and one-way analysis of variance with Tukey's HSD for post-hoc pairwise comparisons, as appropriate.

## Results

### Item Analysis

There were no differences between samples based on child age,  $t(946) = 0.62$ ,  $p = .537$ , child gender,  $\chi^2(1, N = 966) = 2.22$ ,  $p = .136$ , child race/ethnicity,  $\chi^2(1, N = 932) = 3.01$ ,  $p = .557$ , HbA1c,  $t(930) = 0.95$ ,  $p = .345$ , or parent relationship to child,  $\chi^2(1, N = 915) = 1.78$ ,  $p = .775$ .

### Child-Report Version

Of children who completed the PAID-C, 94.4% ( $N = 759$  of 804) did not have any missing items, 4.4% ( $N = 42$ ) had one missing item, 0.5% ( $N = 4$ ) had two missing items, and 0.7% ( $N = 6$ ) of children had more than two missing items. Using Sample 1 ( $N = 409$ ), no items were deleted due to skewness, kurtosis, floor effects, or ceiling effects. All remaining items revealed item-total correlations of 0.4 or higher. KMO was 0.95 and the Bartlett's Test of Sphericity was significant,  $\chi^2(325) = 4,705.08$ ,  $p < .001$ , indicating an analyzable correlation matrix. Parallel analysis indicated two factors. One factor represented *emotional burden* (e.g., "Feeling angry when I think about having diabetes.") and the other factor represented *regimen-specific distress* (e.g., "Feeling like my parents don't trust me to care for my diabetes," "Feeling that I am often failing with my diabetes regimen"). Fifteen items were deleted due to low communalities <0.4. All items had high factor loadings (>0.4) and the two factors accounted for 54.6% of the variance (Rotation Sums of Squared Loadings = 4.8, 4.3). See Table 2 for EFA factor loadings. Cronbach's  $\alpha$  for the resulting 11-item measure was strong for the total scale ( $\alpha = .91$ ) and each factor (*emotional burden*, 4 items,  $\alpha = .86$ ; *regimen-specific distress*, 7 items,  $\alpha = .87$ ).

Using Sample 2 ( $N = 395$ ), CFA of the model with two correlated factors showed adequate model fit (RMSEA = 0.06 [90% CI = 0.04–0.07], CFI = 0.95, TLI = 0.94, SRMR = 0.05). Standardized factor loadings for the *emotional burden* factor ranged from 0.68 to 0.79 and for the *regimen-specific distress* factor from 0.60 to 0.72. Factors were strongly correlated,  $r = .70$ . As a competing model to the two-factor model, a one-factor model was assessed and did not provide adequate fit (RMSEA = 0.10 [90% CI = 0.08–0.11], CFI = 0.85, TLI = 0.81, SRMR = 0.07). See Table 3 for CFA factor loadings.

### Parent-Report Version

Of parents who completed the P-PAID-C, 95.2% (922 of 968) did not have any missing items, 4.3% ( $N = 42$ ) had one missing item, 0.2% ( $N = 2$ ) had two missing items, and 0.2% ( $N = 2$ ) had more than two missing items. Using Sample 1 ( $N = 484$ ), three items on the initial 26-item P-PAID-C were deleted due to floor effects. KMO was 0.93 and the Bartlett's Test of

**Table II.** EFA Factor Loadings for Two-Factor PAID-C and P-PAID-C

No.	Item <sup>a</sup>	Child		Parent/caregiver	
		Factor 1: emotional burden	Factor 2: regimen-specific distress	Factor 1: emotional burden	Factor 2: regimen-Specific distress
4	Angry	<b>-0.82</b>	-0.04	<b>0.74</b>	-0.14
1	Sad	<b>-0.80</b>	-0.03	<b>0.87</b>	-0.23
3	Overwhelmed	<b>-0.61</b>	0.21	<b>0.63</b>	0.09
8	Tired of diabetes	<b>-0.57</b>	0.28	<b>0.57</b>	0.15
5	Food/eating	<sup>b</sup>	<sup>b</sup>	<b>0.66</b>	0.06
6	Complications	<sup>b</sup>	<sup>b</sup>	<b>0.78</b>	-0.04
7	Management "off track"	<sup>b</sup>	<sup>b</sup>	<b>0.71</b>	0.14
9	Not checking enough	<sup>b</sup>	<sup>b</sup>	-0.11	<b>0.77</b>
12	High numbers	<sup>b</sup>	<sup>b</sup>	<b>0.48</b>	0.35
14	Parent mistrust	0.10	<b>0.86</b>	-0.02	<b>0.74</b>
19	Blame from parents	0.13	<b>0.83</b>	<sup>b</sup>	<sup>b</sup>
13	Friends/family as "diabetes police"	-0.03	<b>0.71</b>	0.23	<b>0.59</b>
20	Friends/family don't understand	-0.16	<b>0.57</b>	<sup>b</sup>	<sup>b</sup>
26	Parent worry about complications	-0.21	<b>0.53</b>	<b>0.71</b>	0.06
15	Perfect in management	-0.21	<b>0.51</b>	<b>0.55</b>	0.25
16	Missing checks	<sup>b</sup>	<sup>b</sup>	0.03	<b>0.75</b>
17	Blood sugars swinging	<sup>b</sup>	<sup>b</sup>	0.35	<b>0.43</b>
18	Failing at regimen	-0.19	<b>0.49</b>	0.37	<b>0.44</b>
2	Mood due to blood sugar	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>
10	How to take care of diabetes	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>
11	Unmotivated	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>
21	Lack of control of eating	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>
22	Weight/appearance	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>
23	Fun and friends	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>
24	Fit in when away from home	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>
25	Low during sports	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>

Note. The cutoff for factor loadings was  $\geq .4$ . EFA = exploratory factor analyses. Bold values represent the items that loaded onto the corresponding factor.

<sup>a</sup>General content indicated and not full item wording.

<sup>b</sup>Item deleted from measure during factor analysis.

Sphericity was significant,  $\chi^2(253) = 5,616.17$ ,  $p < .001$ , indicating an analyzable correlation matrix. Parallel analysis indicated two factors. One factor represented *emotional burden* ("Feeling sad when I think about my child having and living with diabetes.") and the other factor represented *child regimen-specific distress* ("Feeling that I cannot trust my child to care for their diabetes."). Seven items were deleted due to low communalities  $< 0.4$ . All remaining items had high factor loadings ( $> 0.4$ ). The two factors accounted for 51.9% of the variance (Rotation Sums of Squared Loadings = 6.2, 4.5). See Table 2 for EFA factor loadings. Cronbach's  $\alpha$  for the resulting 16-item measure was strong for the total scale ( $\alpha = .92$ ) and each factor (*emotional burden*, 10 items,  $\alpha = .91$ ; *child regimen-specific distress*, 6 items,  $\alpha = .85$ ). See Table 2 for all deleted and retained items on the parent version and child version of the PAID.

Using Sample 2 ( $N = 484$ ), CFA of the model with two correlated factors did not provide adequate fit (RMSEA = 0.10 [90% CI = 0.09–0.11], CFI = 0.84, TLI = 0.82, SRMR = 0.07). A competing one-factor model also did not provide adequate fit (RMSEA = 0.12 [90% CI = 0.11–0.13], CFI = 0.77, TLI = 0.73,

SRMR = 0.08). Although parents of children and parents of teens may differ in the dimensions of diabetes-specific distress that they experience, given that the two-factor structure did not fit the data during CFA, a second-order model with four first-order factors was investigated as another possible model for the P-PAID-C. This factor structure was supported during CFA analysis of the P-PAID-T for parents of teens (Shapiro et al., 2017) and a four-factor model could similarly represent the dimensions of distress experienced by parents of younger children. A four-factor model was first identified using EFA with the Sample 1 data of the 16-item P-PAID-C scale. The four-factor model with EFA showed factors of *negative emotions*, *keeping up with chronic demands*, *personal regimen-specific distress*, and *child regimen-specific distress*, similar to factors found for the parent of teen version (Shapiro et al., 2017). Using the Sample 2 data, fit was adequate for the second-order model with four first-order factors, RMSEA = 0.08 [90% CI = 0.07–0.09], CFI = 0.91, TLI = 0.90, SRMR = 0.06). Standardized factor loadings for the *negative emotions* factor ranged from 0.66 to 0.77, *keeping up with chronic demands* from 0.81 to 0.84, *personal regimen-specific distress* from 0.71 to 0.84, and *child*

**Table III.** CFA Standardized Factor Loadings for Two-Factor PAID-C and Four-Factor P-PAID-C

No.	Item <sup>a</sup>	PAID-C (child measure)		P-PAID-C (parent/caregiver measure)			
		Factor 1: emotional burden	Factor 2: regimen-specific distress	Factor 1: negative emotions	Factor 2: keeping up with chronic demands	Factor 3: personal regimen-specific distress	Factor 4: child regimen-specific distress
4	Angry	<b>0.79</b>	c	<b>0.66</b>	b	b	b
1	Sad	<b>0.77</b>	b	<b>0.70</b>	b	b	b
3	Overwhelmed	<b>0.74</b>	b	b	<b>0.81</b>	b	b
8	Tired of diabetes	<b>0.68</b>	c	b	<b>0.84</b>	b	b
5	Food/eating	c	c	<b>0.71</b>	b	b	b
6	Complications	c	c	<b>0.75</b>	b	b	b
7	Management “off track”	c	c	<b>0.77</b>	b	b	b
9	Not checking enough	c	c	b	b	b	<b>0.69</b>
12	High numbers	c	c	b	b	<b>0.75</b>	b
14	Parent mistrust	b	<b>0.72</b>	b	b	b	<b>0.76</b>
18	Failing at regimen	b	<b>0.66</b>	b	b	<b>0.84</b>	b
19	Blame from parents	b	<b>0.65</b>	c	c	c	c
20	Friends/family don’t understand	b	<b>0.64</b>	c	c	c	c
13	Friends/family as “diabetes police”	b	<b>0.63</b>	b	b	b	<b>0.74</b>
26	Parent worry about complications	b	<b>0.63</b>	<b>0.74</b>	b	b	b
15	Perfect in management	b	<b>0.60</b>	b	b	<b>0.71</b>	b
16	Missing checks	c	c	b	b	b	<b>0.82</b>
17	Blood sugars swinging	c	c	b	b	<b>0.72</b>	b

Note. The cutoff for factor loadings was  $\geq .4$ . CFA = confirmatory factor analysis; PAID-C = Problem Area in Diabetes—child version; P-PAID-C = Problem Area in Diabetes—parent version. Bold values represent the items that loaded onto the corresponding factor.

<sup>a</sup>General content indicated and not full item wording.

<sup>b</sup>Item did not load on that factor.

<sup>c</sup>Item deleted from measure during factor analysis.

regimen-specific distress factor from 0.71 to 0.84. Standardized loadings for each first-order factor on the second-order *diabetes-specific distress* factor ranged from 0.65 (*child regimen-specific distress*) to 0.94 (*negative emotions*). See Table 3 for CFA factor loadings.

### Validity

Evidence for *criterion validity* was observed for the PAID-C, as scores were negatively correlated with youth-reported diabetes-related strengths ( $r = -.38$ ,  $p < .001$ ), and positively correlated with parent report of HbA1c ( $r = .08$ ,  $p = .040$ ). Youth scores on the PAID-C were not significantly correlated with self-care skills ( $r = -.07$ ,  $p = .062$ ). Evidence for *criterion validity* was also observed for the P-PAID-C, as scores were negatively correlated with youth-reported diabetes self-care skills ( $r = -.13$ ,  $p < .001$ ) and youth-reported diabetes-related strengths ( $r = -.29$ ,  $p < .001$ ), and were positively correlated with HbA1c ( $r = .18$ ,  $p < .001$ ). Total scores on the PAID-C were significantly correlated with total scores on the P-PAID-C ( $r = .40$ ,  $p < .001$ ).

### Diabetes-Specific Emotional Distress

Children reported diabetes-specific emotional distress with a mean score of  $28.6 \pm 12.0$  (range: 11–66; each item scored on a 1–6 scale where 1 = *Not a Problem*

and 6 = *Big/Serious Problem*). About 40% (40.9%) reported at least one item that was a “Serious Problem” for them, with an average of  $1.4 \pm 2.3$  serious problems reported (range: 0–11). Most frequently endorsed concerns were feeling that “friends/family do not understand how hard it can be to live with diabetes” (26.8%), feeling “sick and tired of always trying to take care of diabetes” (22.9%), feeling as though “parents worry about bad things happening” to them (21.7%), and feeling that friends/family are “nagging about food or about checking blood sugars” (20.5%).

Caregivers reported diabetes-specific emotional distress when caring for their child with T1D with a mean score of  $48.3 \pm 15.2$  (range: 16–96). Additionally, 61.1% of parents reported at least one serious concern, with an average of  $2.8 \pm 3.4$  serious concerns (range: 0–16). The most common concerns were “worrying about the future and the possibility of serious complications” (36.6%), “feeling upset when my child’s diabetes management is off track” (34.0%), “feeling constantly concerned about food and eating” (24.2%), “feeling like the diabetes police” (22.6%), and “feeling ‘burned-out’ by the constant effort to manage my child’s diabetes” (20.3%).

### Demographic Differences in Diabetes Distress

Youth report of distress was significantly different based on child race/ethnicity,  $F(3, 742) = 2.71$ ,  $p = .044$ , with post-hoc pairwise comparisons indicating that African American youth-reported greater distress than Caucasian youth ( $d = 0.55$ ,  $p = .050$ ). Youth report of distress also differed based on mother's education level,  $F(4, 763) = 5.78$ ,  $p < .001$ , with youth of mothers with less than a high school degree or completing some college reporting greater distress than those with a mother who had completed a college degree ( $d = 0.92$ ,  $p = .031$ ;  $d = 0.40$ ,  $p = .001$ , respectively). Additionally, child distress varied based on household income, such that distress was significantly greater among families with incomes reported of  $< \$25,000$  when compared with all income categories greater than  $\$25,000$  ( $\$26\text{--}50\text{k}$ ,  $d = 0.43$ ,  $p = .097$ ;  $\$51\text{--}75\text{k}$ ,  $d = 0.60$ ,  $p = .013$ ;  $\$76\text{--}100\text{k}$ ,  $d = 0.55$ ,  $p = .017$ ;  $\$101\text{--}125\text{k}$ ,  $d = 0.64$ ,  $p = .002$ ;  $\$126\text{--}150\text{k}$ ,  $d = 0.61$ ,  $p = .028$ ;  $\$151\text{--}175\text{k}$ ,  $d = 0.82$ ,  $p = .001$ ;  $> \$175\text{k}$ ,  $d = 0.70$ ,  $p = .001$ ). There was a significant overall difference in distress based on mother's marital status,  $F(5, 761) = 2.9$ ,  $p = .011$ , and father's education,  $F(4, 748) = 3.2$ ,  $p = .012$ , but no significant subgroup differences emerged in post-hoc pairwise comparisons. Youth report of distress was not significantly associated with child age ( $r = .02$ ,  $p = .689$ ), child sex,  $t(768) = -0.99$ ,  $p = 0.323$ , or mode of insulin delivery,  $F(2, 767) = 1.2$ ,  $p = .312$ .

With regard to parent-reported distress, there was a significant difference based on child race/ethnicity,  $F(3, 925) = 11.97$ ,  $p < .001$ , such that caregivers of African American youth reported greater distress than caregivers of Caucasian youth ( $d = 1.05$ ,  $p < .001$ ). Similar to child-reported distress, pairwise comparisons revealed differences in parental distress based on reported income category, with those reporting  $< \$25,000$  income endorsing greater distress than those reporting income of  $\$76\text{--}100\text{k}$  ( $d = 0.47$ ,  $p = .015$ ) and  $\$151\text{--}175\text{k}$  ( $d = 0.73$ ,  $p = .002$ ), and  $> \$175\text{k}$  ( $d = 0.51$ ,  $p = .018$ ). Consistent with child-reported distress, there were differences in parent-reported distress based on maternal,  $F(4, 957) = 3.5$ ,  $p = .008$ , and paternal education level,  $F(4, 933) = 4.9$ ,  $p = .001$ ; with those completing a college degree reporting less overall distress than those completing only some college ( $d = 0.27$ ,  $p = .015$  maternal,  $d = 0.29$ ,  $p < .001$  paternal). There were overall significant differences in parent-reported distress based on maternal marital status,  $F(5, 953) = 3.4$ ,  $p = .005$ ; however, post-hoc analyses indicated no significant differences between subgroups. Parent report of distress did not differ significantly based on child age ( $r = -.3$ ,  $p = .448$ ), child sex,  $t(961) = .11$ ,  $p = .914$ , or mode of insulin delivery,  $F(2, 959) = 1.3$ ,  $p = 0.284$ .

### Discussion

This study provides analyses of the psychometric properties of adapted measures of diabetes-specific emotional distress for children with T1D (PAID-C) and their caregivers (P-PAID-C). While measures of diabetes-specific distress have been validated among adolescents with T1D and caregivers (Shapiro et al., 2017), this is the first known psychometric validation of a measure of diabetes-specific emotional distress for younger children. Both the PAID-C and the P-PAID-C demonstrate excellent internal consistency ( $\alpha = .91$  and  $.92$ , respectively).

The child measure of diabetes distress captured two factors: the emotional burden of diabetes and regimen-specific difficulties. For the parent measure, EFA indicated two similar factors of emotional burden of diabetes and feelings of ineffectiveness in managing the child's diabetes regimen. However, the CFAs did not support a two-factor structure or a competing one-factor model. Rather, a four-factor model of distress for parents of children was supported, which mirrors the four-factor structure of the P-PAID-T for parents of teens (Shapiro et al., 2017). Given this difference, no clear determination can be made regarding the number of dimensions of distress for the parent measure at this time. At this time, for clinical and research purposes, it is most useful to interpret the parent and child versions of this instrument using summed total scores. A summed score represents the overarching construct of diabetes distress. The second-order model for the P-PAID-C provided adequate fit and the CFA model with two correlated factors for the PAID-C provided adequate fit with a high correlation between the two PAID-C factors (this model is statistically equivalent to a second-order CFA with two first-order factors). These analyses provide validity for the use of summed total scores when interpreting the measures.

Comparison with the teen and parent of teen versions (Shapiro et al., 2017) reveals similar components of diabetes distress for the child and parent of child measures. However, dissimilar from the teen version, the PAID-C did not include a third factor related to feeling unsupported by family and friends (e.g., blame from parents, T1D gets in the way of time with friends). From a developmental perspective these differences are expected, as adolescents are more likely to prioritize friendships and they are gaining more independence from their parents. The P-PAID-C also retained items relating to perceptions of needing to be perfect and concerns about a child's lack of control over eating, which were excluded in the parent of teen version. This finding is also consistent with a developmental perspective, as parents of younger children are primarily responsible for their children's dietary choices and day-to-day care, whereas adolescents

begin to develop more independence in these areas. These differences highlight the importance of having distinct validated measures of diabetes-specific distress for younger children and their caregivers that reflect the unique developmental differences.

Comparison of items across the final version of the PAID-C and P-PAID-C revealed that caregivers expressed greater concern related to their child's eating behaviors and blood glucose monitoring than children themselves. These differences may be due to parents' better understanding of the impact of diet and blood glucose checking on diabetes management and the long-term implications of health behaviors. Parents are also primarily making the decisions about the types of foods their children eat and have access to on a daily basis. Differences in items retained between the child measure and the parent measure are likely due to the inherent differences in their roles (living with diabetes versus caring for someone with diabetes) and in age and developmental level. For example, parents typically have more responsibility for carrying out diabetes management tasks than do their children, resulting in a greater awareness of the execution and overall management of these tasks and potentially greater distress due to a sense that their child cannot complete diabetes tasks independently. In contrast, children report more distress in relation to the actual lived experience of diabetes, such as daily injections and blood sugar checks. These important differences may inform the unique interventions and support needed for caregivers and for children.

Results suggest that the PAID-C and P-PAID-C demonstrate strong validity. Both measures were positively associated with HbA1c and negatively associated with child-reported diabetes strengths. The P-PAID-C was also negatively correlated with parent-rated diabetes self-care skills. These findings replicate previous research using the PAID and PAID-T measures with adults (Polonsky et al., 1995; Shapiro et al., 2017; Welch, Jacobson, & Polonsky, 1997) in this new population of preadolescent children. The positive association between the P-PAID-C and hemoglobin A1c is supported by previous research showing that higher parenting stress is related to worse glycemic control in adolescents (Maas-van Schaijk, Roeleveld-Versteegh, & van Baar, 2013). In contrast, other studies using more general measures of parenting stress showed that higher rates of parenting stress was associated with improved glycemic control (Helgeson, Becker, Escobar, & Siminerio, 2012; Stallwood, 2005). The difference in findings across these studies may be due to the different measures used, as the P-PAID-C was specifically designed to capture the unique experiences of parenting related to T1D management and may have greater relevance to glycemic control. Notably, the association between

diabetes distress and HbA1c accounted for a small portion of the overall variance. This may be due to the limited variability in HbA1c values. Alternatively, it is also possible that the relation between A1c and distress is, in fact, statistically significant but small. This is consistent with prior research on diabetes distress and HbA1c that has found small-to-moderate effect sizes (e.g., for teens, Hagger et al 2016). This suggests that diabetes distress is a significant predictor of HbA1c, but other factors, such as adherence behaviors and parental involvement, also impact HbA1c.

Diabetes distress varied based on demographic factors, including race/ethnicity of the child, family income level, and maternal education level. The finding that Black/African American youth and caregivers reported greater distress than Caucasian participants is consistent with prior research revealing higher levels of diabetes distress in minority youth (Delamater, Patiño-Fernández, Smith, & Bubb, 2013; Fegan-Bohm et al., 2016). These findings are important, as they highlight the health disparities that exist within the pediatric diabetes population. Recent studies have also found that ethnic minority youth with T1D are at a significantly greater risk for poor glycemic control over time and for diabetes complications compared with non-Hispanic White youth with T1D (Redondo et al., 2018). These findings may be closely associated with the increased levels of distress found within ethnic minority youth with T1D. Future studies should examine what may contribute to greater distress among minority youth, such as psychosocial stressors associated with minority status (e.g., low socioeconomic status (SES), racial health disparities, social determinants of health, and underrepresentation in intervention research). Additionally, lower-income and educational attainment were associated with greater distress, suggesting potential vulnerability based on SES.

Distress did not vary based on child's sex, which is in contrast with prior research reporting higher levels of diabetes distress among adolescent females (Lašaitė, Ostrauskas, Žalinkevičius, Jurgevičienė, & Radzevičienė, 2016; Shapiro et al., 2017). These findings are consistent with literature demonstrating that there are similar rates of preadolescent depression based on gender, but depression rates increase for females in adolescence (Costello, Mustillo, Erkanli, Keeler, & Angold, 2003). Diabetes-specific distress may function similarly, with equitable rates among male and female youth, and higher distress among teenage girls. Longitudinal research is needed to examine developmental trends in diabetes distress.

The results should be considered in the context of limitations of the current study. The participants were largely Caucasian, highly educated, and reported high household income. In addition, families who participate in diabetes camps may be different from families



who do not, whether due to limited access (financially or geographically), awareness, or interest. This may limit the generalizability of the current results, as caregivers who are less connected to diabetes-related resources like camp may experience different levels of diabetes-specific emotional distress. Additionally, measures of HbA1c and self-management skills were parent-reported, and are vulnerable to inaccuracies in memory and social desirability bias. While there are studies to support retrospective reporting of HbA1c (Hessler et al., 2016; Weissberg-Benchell, Rausch, Iturralde, Jedraszko, & Hood, 2016; Weissberg-Benchell & Rychlik, 2017), future research using the PAID-C and P-PAID-C should involve a medical chart review to obtain HbA1c levels. Additional measures of depression, nondiabetes specific stress, family conflict due to diabetes, and overall psychological functioning were not included in the present validity analyses and should be evaluated through future research based on prior studies suggesting relations between diabetes distress and these variables in other age groups (Shapiro et al., 2017; Weissberg-Benchell & Antisdell-Lomaglio, 2011; Weissberg-Benchell et al., 2014). Future studies might use a measure of nondiabetes distress to establish construct validity for the PAID-C and P-PAID-C and for the purpose of identifying an appropriate cutoff score for these measures. In the absence of this information, it is suggested that clinicians and researchers base the cutoff on population distribution, in which a score is deemed high or low if the total score is 1 *SD* above or below the mean. Additionally, due to developmental differences across children and teens, an EFA was used to analyze the PAID-C measures despite already having an existing factor structure for the PAID-T measures. This resulted in different factor structures across the child and teen measures. These different factor structures across age groups and parents introduces limitations with regard to implementation of the measures and when conducting longitudinal research. Future studies may assess equivalence of PAID measurement models for children versus teens to empirically test the theory that there are differences in the manifestation and measurement of diabetes distress based on age group. In addition, future research can assess validity and utility of using subscale scores based on factors identified in the current study.

The current analyses relied on one time-point only; therefore, in order to further establish the reliability and validity of the PAID-C and P-PAID-C it is recommended that future studies involve administration of these measures in their newly revised form, to the same population, to assess test-retest reliability. Lastly, the present study investigates a number of key components of new measure development according to Holmbeck and Devine (2009), but future research

is needed to further assess psychometric properties of discriminant validity, predictive validity, and diagnostic utility of the PAID-C and P-PAID-C.

Diabetes-specific emotional distress is associated with both psychological and health outcomes (Bernstein et al., 2013; Herzer & Hood, 2010; Hilliard et al., 2011; Yi-Frazier et al., 2015) making regular screening in children and parents critical. The PAID-C and the P-PAID-C have strong potential to be used for routine screening during clinic visits, as they are brief and can be discussed during the visit. The identification of specific areas of distress for each child and his/her caregivers can facilitate focused support and referrals. In brief, targeted assessment of diabetes-specific emotional distress will lead to more timely interventions that can prevent or curb the development of significant psychological distress and poor health outcomes.

### Author Note

The PAID-C and the P-PAID-C are available from Jill Weissberg-Benchell at JWBenchell@luriechildrens.org upon request.

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