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Original Research Article

Development and Validation of the Parent-Preschoolers Diabetes Adjustment Scale (PP-DAS)

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Abstract

Objective This article extends work on a social-ecological model of caregiver adjustment and describes the: (a) development and (b) validation of the Parent-Preschoolers Diabetes Adjustment Scale (PP-DAS), a broad measure of caregiver adjustment. **Methods** Participants were caregivers ($n_{\text{study1}} = 51$; $n_{\text{study2}} = 177$) of very young children (<6 years old) with Type 1 diabetes (T1D). In study 1, researchers and stakeholders collaborated to develop 92 items using the 5 domains of a social-ecological model of caregiver adjustment to the challenges of raising a very young child with T1D, and parents and researchers provided feedback on these items. In study 2, confirmatory factor analysis (CFA) and exploratory factor analysis (EFA) were used to examine the factor structure of the PP-DAS. Reliability and validity were also examined. **Results** After review by parents and researchers, 52 items were removed resulting in the 40-item version used in study 2. The CFA demonstrated poor fit with the five proposed domains of the social-ecological model, so an EFA was conducted and supported a different five-factor solution. Twenty items were removed due to low factor loadings or communalities, resulting in a final 20-item measure. The PP-DAS demonstrated adequate internal consistency (α's = .73–.84), convergent validity with parent psychological functioning and self-efficacy in T1D management, and criterion validity with hemoglobin A1c and adherence. **Conclusions** The PP-DAS is a valid and reliable measure of adjustment in caregivers of very young children with T1D. The PP-DAS may help identify caregivers who are having adjustment difficulties and would benefit from additional support.

Key words: coping skills and adjustment; diabetes; parents; psychosocial functioning.

Type 1 diabetes (T1D) is one of the most commonly diagnosed chronic illnesses in children and adolescents (Pettitt et al., 2014). Youth with T1D and their families must adhere to a complex treatment regimen in which youth and/or their caregivers must check their blood sugar multiple times, count carbohydrates at every meal and snack, and calculate and deliver insulin doses based on food intake, physical activity, and other factors that can affect blood glucose levels (National Institutes of Health [NIH], 2017). Nonadherence with one or more of these components of the regimen can result in adverse acute and long-term health outcomes (NIH, 2017). Not surprisingly, T1D management places considerable stress on youth of all ages and their families (Whittemore, Jaser, Chao, Jang, & Grey, 2012), and caring for a very young child (<6 years old) with T1D presents additional challenges (Patton, Dolan, Smith, Thomas, & Powers, 2011; Powers et al., 2002; Streisand & Monaghan, 2014).

Very young children are completely reliant on their caregivers (Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2002), which may place more responsibility for diabetes management on these caregiver than caregivers of older children (Streisand & Monaghan, 2014). Preschool-aged children also have lower levels of emotional and behavioral regulation (Cole, Dennis, Smith-Simon, & Cohen, 2009), and they may need additional support in order to complete aspects of their regimen (e.g., sitting still for injections). Caregivers of very young children must also deal with less predictable patterns of eating (Cathey & Gaylord, 2004) and physical activity (Bailey et al., 1995), which may lead to suboptimal T1D management (e.g., dosing insulin after meals, keeping blood sugars higher to avoid unexpected hypoglycemia; Patton, Dolan, Henry, & Powers, 2007; Patton et al., 2011). Finally, very young children are more sensitive to the pharmacological effects of insulin, frequently experience nocturnal hypoglycemia, and may be at greater risk for neurocognitive sequelae of suboptimal T1D management (Marzelli et al., 2014; Porter, Keating, Byrne, & Jones, 1997).

Altogether, caregivers of very young children with T1D face many challenges and may experience adjustment difficulties. Broadly, adjustment is defined as a caregiver's ability to adapt to the challenges associated with the demands of caring for a young child with T1D (Sharpe & Curran, 2006). Although some difficulty adjusting to these demands is normative, caregivers who adjust well may feel less challenged by the demands of caring for a child with T1D. Pierce, Aroian, et al. (2017) used qualitative crowdsourcing methods to gain insights into caregiver adjustment to the day-to-day challenges of caring for a young child with T1D. Qualitative findings revealed that challenges in caring for a young child with T1D occur at all levels of a social-ecological framework: (a) Child with T1D (e.g., managing their child's T1D, helping their child adjust to living with T1D), (b) Parents as Individuals (e.g., managing their own psychological functioning related to their child's T1D diagnosis), (c) Family (e.g., working with their spouse to manage child's T1D, balancing time with their non-T1D children), (d) Social Environment (e.g., obtaining adequate support from friends and relatives), and (e) Healthcare Community (e.g., learning to navigate a new healthcare system, feeling satisfied with child's T1D care team). Consequently, adjustment may be more specifically conceptualized as a multidimensional construct with adjustment challenges occurring at all levels of a social-ecological framework.

Research on caregiver adjustment in young children with T1D focuses almost exclusively on one social-ecological level of adjustment, the Parents as Individuals level. There is a growing body of literature examining psychological functioning of caregivers of young children with T1D, which encompasses parenting stress, parenting distress, and symptoms of mental health disorders. Caregivers of youth with T1D are at increased risk for experiencing symptoms of posttraumatic stress, anxiety, and depressive disorders soon after their child is diagnosed with T1D (Landolt, Vollrath, Ribi, Gnehm, & Sennhauser, 2003; Landolt et al., 2002; Noser et al., 2019; Patton et al., 2011; Streisand et al., 2008), and up to 4 years postdiagnosis (Whittemore et al., 2012). Furthermore, caregivers of very young children with T1D report more parenting stress and symptoms of anxiety and depression than caregivers of older youth with T1D (Hilliard, Monaghan, Cogen, & Streisand, 2011; Jaser, Whittemore, Ambrosino, Lindemann, & Grey, 2009; Wysocki, Huxtable, Linscheid, & Wayne, 1989). Furthermore, caregiver mental health symptoms and distress appear to be associated with health (Cunningham, Vesco, Dolan, & Hood, 2010) and psychosocial (Eckshtain, Ellis, Kolmodin, & Naar-King, 2010) outcomes for very young children with T1D.

Taken together, psychological functioning appears to be one important marker of overall caregiver adjustment to T1D. However, little research has examined how caregivers adjust to T1D across the other social-ecological levels (i.e., Child, Family, Social Environment, and Healthcare Community), which negates the multidimensional nature of this construct. This may be, in part, due to the lack of valid instruments that measure the other four domains of caregiver adjustment proposed by Pierce, Aroian, et al. (2017). In order to comprehensively assess caregiver adjustment and examine the impact of interventions across all domains of the social-ecological framework, a broader assessment tool is required.

The findings from two studies are presented in this article. The aim of the first study was to use crowdsourcing strategies and stakeholder engagement to develop the item pool for a measure of adjustment in caregivers of preschool-aged children (<6 years old) with T1D, the Parent-Preschool Diabetes Adjustment Scale (PP-DAS). The aims of the second study were to evaluate the factor structure and psychometric properties of the PP-DAS. It was hypothesized that the PP-DAS items would load on to five factors consistent with the five social-ecological domains proposed by Pierce, Aroian, et al. (2017). It was also hypothesized that the PP-DAS would demonstrate validity through significant bivariate correlations with measures of theoretically similar constructs (i.e., convergent validity) and a key clinical outcome (i.e., criterion validity).

Study 1: Development of the PP-DAS

Methods

All study procedures were approved by the Nemours institutional review board.

Participants and Procedures

The items, response format, and instructions for the PP-DAS were developed through an iterative process involving input from members of the research team and caregivers of youth with T1D. The research team consisted of two pediatric psychologists, a pediatric endocrinologist, and a nurse researcher with expertise in qualitative research methods and measurement development. Six parents of very young children with T1D were selected to be family advisors, whose role was to represent participant perspectives as members of the research team (Pierce, Aroian, et al., 2017).

The research team and family advisors used coded qualitative data from the crowdsourcing study (Pierce, Aroian, et al., 2017) to develop the items for the PP-DAS. Participants in the crowdsourcing study were 157 parents of children with T1D who were diagnosed before age 6. They responded to a series of open-ended questions that assessed the impact of T1D on parents, the child, family and other social relationships, and interactions with the healthcare system (e.g., "In what ways has your life changed since your child was diagnosed with T1D," "What challenges are you facing in managing your child's T1D?"). While analyzing caregivers' responses it became apparent that caregivers' experiences aligned with a social-ecological framework (i.e., Child, Parents, Family, Social Environment, and Healthcare Community), but also that a measure to assess caregiver adjustment across all five of these domains was lacking. In order to create such a questionnaire, the research team reviewed the qualitative responses and generated items that reflected caregivers' experiences. The family advisors reviewed the items and provided open-ended feedback. Over the course of four iterations, the research team and family advisors created a 92-item version of the PP-DAS that was subjected to review by participants in the crowdsourcing study for item reduction and refinement.

All participants from the crowdsourcing study (Pierce, Aroian, et al., 2017) were invited to provide input on reduction and refinement of the PP-DAS. Crowdsourcing participants previously completed a questionnaire that asked about parent and child demographics and T1D variables (e.g., hemoglobin A1c [HbA1c], use of continuous glucose monitors [CGM], and type of regimen). Of the 153 participants in the ongoing crowdsourcing study, 51 (33.3%) provided input on the PP-DAS. Those 51 participants received a description of the purpose of the PP-DAS (i.e., to measure parental adjustment to the challenging's of T1D in the upcoming randomized controlled trial) and the 92-items developed by the research team and family advisors. In order to reduce respondent burden and obtain input on items that were the clearest in capturing the intended meaning, parents were instructed to rate each of the 92 items as "keep" or "delete," and provide optional open-ended comments about each item. Participants received examples of reasons they may choose to keep (e.g., "The question is very representative of the experience of a parent of a young child with T1D") or delete (e.g., "The question is already covered by another item that you would rather keep") items. Participants were paid $10 for participating. Items that were rated as "delete" by ≥20 parents were removed. Research staff and family advisors then reviewed the remaining items and participant feedback.

Results

Descriptive Statistics

Three of the 51 parents who provided feedback on the PP-DAS did so anonymously; therefore, demographics are available for only 48 of the 51 participants (Table I). Participants were predominantly female ($n = 45$, 93.8%), Caucasian ($n = 43$, 91.5%), and had an education level of some college or higher ($n = 45$, 93.8%). The mean HbA1c for the study sample (M = 7.60, SD = 0.73) was slightly above the American Diabetes Association (ADA) recommended level of 7.5%.

Item Development

Researchers and family advisors created 92 items that were developed to measure the five domains of Pierce, Aroian, et al's (2017) social-ecological framework: Child (20 items), Parent (14 items), Family (29 items), Social Circle (18 items), and Healthcare Community (11 items). Then, 51 participants rated all 92 items of first draft of the PP-DAS. Forty-one items were rated as "delete" by at least 20 parents and were consequently deleted. Researchers and family advisors decided to retain one item that the parent crowd members wanted to delete ("My other child(ren) are treated unfairly because of my child's T1D") because it was thought to be conceptually important and not addressed by other items. This resulted in a 52-item version of the PP-DAS with items representing the Child (11 items), Parent (9 items), Family (13 items), Social Circle (9 items), and Community and Healthcare (10 items) domains.

Next, the research team and family advisors reviewed the remaining 52 items of the PP-DAS for clarity and ambiguity. Research team members and

Table I. *Demographics and Clinical Characteristics of Children with T1D and Caregivers*

	Study 1 ($n = 51$)		Study 2 ($n = 177$)	
Variable	Percent (*n*)	Mean (*SD*), [Range]	Percent (*n*)	Mean (*SD*), [Range]
Youth age (years)		5.73 (1.99), [2.00–9.00]		3.82 (1.28), [0.80–6.08]
Caregivers age (years)		37.02 (5.57), [24.00–46.00]		34.28 (5.90), [20.00–68.00]
Duration of T1D (years)		2.60 (1.79), [0.00–7.00]		1.63 (1.17), [0.00–5.33]
Most recent HbA1c (%)[a]		7.60 (.73), [6.10–9.40]		7.74 (1.24), [5.40–15.40]
Gender, % (*n*) female				
Youth	54.5 (24)		44.3 (78)	
Caregiver	93.8 (45)		92.0 (162)	
Race, % (*n*) Caucasian				
Youth	87.5 (42)		85.7 (150)	
Caregiver	91.5 (43)		91.4 (160)	
Ethnicity, % (*n*) Non-Hispanic				
Youth	88.9 (40)		89.7 (157)	
Caregiver	95.8 (46)		94.9 (167)	
Insulin regimen				
Insulin pump	68.9 (31)		59.3 (105)	
Multiple daily injections	31.1 (14)		40.7 (72)	
Use of continuous glucose monitor, % yes	64.4 (29)		84.7 (150)	
Relationship to child				
Mother (Biological/Adoptive/Step)	91.7 (44)		92.1 (163)	
Father (Biological/Adoptive/Step)	8.3 (4)		7.9 (14)	
Parent education				
Less than 7th grade			0.6 (1)	
HS diploma	6.3 (3)		10.7 (19)	
Some college/technical school	22.9 (11)		32.8 (58)	
Bachelor's degree	33.3 (16)		33.9 (60)	
Graduate degree	37.5 (18)		22.0 (39)	
Household annual income				
<\$25K	12.8 (6)		10.9 (19)	
\$25K–49K	17.0 (8)		19.5 (34)	
\$50K–\$74K	23.4 (11)		17.8 (31)	
\$75K–\$99K	12.8 (6)		17.2 (30)	
\$100K–\$149K	25.5 (12)		19.5 (34)	
≥\$150K	8.5 (2)		15.0 (26)	

[a] HbA1c values for study 1 were all self-report and for study 2 were obtained from labs ($n = 138$) or self-report ($n = 39$).

family advisors elected to remove 11 additional items because they overlapped with items from different domains ($n = 7$), there were concerns that the wording of the question may bias responses or limit response variability ($n = 3$), or the item was not be applicable to most parents ($n = 1$). The researchers and family advisors also combined two items that were thought to be too similar. This resulted in a final 40-item version of the PP-DAS that was used in the validation study.

Study 2: Validation of the PP-DAS

Methods

All study procedures were approved by the organization's institutional review board, including waiver of informed consent documentation to obtain electronic informed consent.

Participants and Procedures

Participants were 177 caregivers of very young children with T1D enrolled in a randomized control trial examining the effects of an online coping intervention on psychosocial and diabetes-related outcomes. Data reported in this article are drawn from the baseline measures completed by these parents. Parents of young children with T1D were recruited from (a) within a national children's health system with sites in the Delaware Valley, and North and Central Florida, (b) diabetes websites, (c) blogs, (d) social media groups for parents of children less than 6 years old with T1D, or (v) contact with North American T1D clinicians. Parents received an email or viewed an online flyer with a description of the study and a link to an electronic informed consent form on Research Electronic Data Capture (REDCap). Parents were eligible for the study if they: (a) were the parent or legal guardian of a child with T1D under 6 years old at the time of informed consent, (b) had access to the internet several times per week, (c) lived in the United States during the study, and (d) could read and write in English. Both parents of a child were encouraged to participate, but were instructed to complete questionnaires separately. After completing the electronic informed consent, participants completed demographic forms and study questionnaires. Participants provided their email address and contact information so research staff could contact them during the study and provide compensation. Participants were paid $25 on a study debit card after completing baseline questionnaires.

Demographic and Health Information Questionnaire (DHIQ) assessed the caregiver and child demographic and diabetes variables reported in Table I.

PP-DAS is a self-report measure of adjustment in parents of preschool-aged children with T1D containing the 40 items retained in Study 1. Parents rated how much statements such as “I feel comfortable helping others understand my child’s T1D” apply to them and their family using a 4-point Likert scale ranging from 0 (*Not at all true*) to 3 (*Absolutely true*). Parents could also rate items as “not applicable” if items did not apply to them or their child (e.g., only have one child for items about siblings, don’t have a spouse or partner). Seventeen items were reverse scored. PP-DAS scores were created by calculating averages of the items to which participants responded on the 0–3 scale, with higher scores indicating better parent adjustment.

Measures of Convergent Validity

Convergent validity of the PP-DAS was evaluated in relation to similar constructs (parental psychological symptoms and self-efficacy). The Brief Symptom Inventory-18 (BSI-18) was used to measure parental psychological symptoms (Derogatis & Fitzpatrick, 2004). Participants indicated how often they experienced symptoms of depression, anxiety, and somatization over the past week on 18 items using a 5-point Likert-type scale ranging from 0 (*not at all*) to 4 (*very much*). T-Scores were calculated for the General Severity Index and three subscales, with higher scores reflecting more frequent and severe symptoms of depression, anxiety, and/or somatization over the past week. In our study, the internal consistency of the three scales ranged from .73 to .86. The Parental Self-Efficacy Scale for Diabetes Management (PSESDM) was used to assess parents’ self-efficacy for managing their child’s diabetes (Marchante et al., 2014). The PSESDM is an 8-item self-report measure where participants rate how much they agreed with items on a 5-point Likert scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Caregivers’ responses were summed to yield a total diabetes self-efficacy score, ranging from 15 to 40, and higher scores indicated that parents were more confident in their ability to manage their child’s diabetes. The PSESDM demonstrated good internal consistency ($\alpha = .82$) in this study. We expected that the PP-DAS scores would be inversely correlated with the BSI-18 subscales and positively correlated with the PSESDM as evidence of convergent validity.

Measure of Criterion Validity

Criterion validity was evaluated in relation to adherence with the child’s diabetes regimen and glycemic control, a key diabetes outcome, that was measured via the child’s most recent HbA1c. Adherence with the diabetes regimen was measured via parent-reports of the Diabetes Self-Management Profile, Self Report, (DSMP-SR; Wysocki, Buckloh, Antal, Lochrie, & Taylor, 2012). The DSMP-SR is a 24-item measure in which parents were asked questions about managing their child’s T1D over the past 3 months. Responses were summed to yield total scores, ranging from 0 to 96, with higher scores indicating more optimal T1D management. HbA1c was collected through labs via a review of the electronic medical record (EMR) (if available), HemaSpot SE Blood Spot Collection Devices (dried blood spot), or parents emailed a copy of their child’s most recent lab report. Most HbA1c values were taken from EMR review or dried blood spots from labs ($n = 138$, 78.0%). Higher HbA1c values indicate higher average blood glucose over the past 2–3 months. We expected that the PP-DAS scores would be positively correlated with DSMP-SR scores and inversely correlated with HbA1c.

Statistical Analysis

Statistical analyses were performed using Mplus v8.3 and IBM SPSS v25. Descriptive statistics (e.g., frequency, mean, and standard deviation) were conducted for demographic, clinical, and variables used in validity analyses. Confirmatory factor analysis (CFA) was used to examine whether the five domains derived from Study 1 represented the underlying factor structure of the PP-DAS. Thus, a five-factor solution was specified. The unweighted least squares means and variances (ULSMV) estimation method was used because provides more accurate estimates for ordinal data with fewer than five response options and when sample size is <200, like in the current study (Rhemtulla, Brosseau-Liard, & Savalei, 2012). Chi-square, RMSEA $< .08$, and CFI $> .90$ were used to determine model fit (Hooper, Coughlan, & Mullen, 2008; Hu & Bentler, 1999).

Exploratory factor analysis (EFA) was proposed to explore alternative factor structures if the CFA demonstrated poor fit for the proposed five-factor solution. An unweighted least squares (ULS) estimation method was used given the ordinal nature of the data and the small sample (Rhemtulla et al., 2012), and direct oblimin (oblique) rotation was used because the factors of the PP-DAS were assumed to be correlated

(Watkins, 2018). Empirical Kaiser criterion and visual inspection of the scree plot were used to determine the number of factors to retain (Braeken & van Assen, 2017; Watkins, 2018). Given the current sample size, factor loadings $\geq .39$ were considered statistically and practically meaningful (Norman & Streiner, 2014). Items with cross-loadings $\geq .30$, or with a difference of $\leq .20$ between the primary and secondary loadings, were examined to determine if they should be rejected. Factors were considered adequate if they had three or more items and were theoretically meaningful. CFA using a robust maximum likelihood estimation method was used to examine a second-order factor structure with subscales identified via the EFA loading onto total score. The same fit indices (χ^2, RMSEA, and CFI) were used to examine model fit. Internal consistencies of the factors identified through the EFA and second-order total score were examined via Cronbach's alpha. Convergent and criterion validity were evaluated via Pearson r correlations between the PP-DAS subscales and the BSI-18, PSESDM, DSMP-SR, and HbA1c.

Results

Demographics and Descriptives

Similar to the first study, participants in study 2 (Table I) were predominantly female ($n = 162$, 92.0%), Caucasian ($n = 160$, 91.4%), and had an education level of some college or higher ($n = 157$, 86.7%). The mean HbA1c for the study sample was slightly above the ADA recommended level of 7.5% ($M = 7.74$, $SD = 1.24$). Descriptive statistics for the variables included in validity analyses are reported in Table II. Skewness and kurtosis statistics indicated that all the distributions of the variables in validity analyses were acceptable.

Table II. *Descriptive Statistics for Parent-Report Measures*

Variables ($n = 177$)	Mean (*SD*)	Min	Max
BSI-18			
Somatization subscale	50.20[a] (9.29)	41	77
Depression subscale	52.36[a] (9.65)	40	75
Anxiety subscale	53.53[a] (10.69)	38	81
PSESDM	32.26[b] (5.08)	15	40
DSMP-SR	60.74[b] (10.34)	26	78
PP-DAS			
Caregiver stress (PPDAS-CS)	1.78[b] (0.74)	0.00	3.00
Emotional functioning (PPDAS-EF)	0.91[b] (0.80)	0.00	3.00
Healthcare (PPDAS-H)	2.49[b] (0.65)	0.00	3.00
Social Circle (PPDAS-SC)	1.92[b] (0.89)	0.00	3.00
T1D Mastery (PPDAS-M)	2.04[b] (0.69)	0.20	3.00

[a] Values for these subscales are t-scores.
[b] Values are raw scores.

Confirmatory Factor Analysis

Results for the CFA indicated that the proposed five-factor model demonstrated poor fit (RMSEA = .06, CFI = .67, X^2 (730) = 1158.28, $p < .001$). Model fit slightly improved after examining modification indices and making theoretically-consistent changes to factor loadings. One fit index continued to indicate good fit (RMSEA = .05), but the other two indicated poor fit (X^2 (584) = 838.79, $p < .001$; CFI = .79). Due to the inconsistent fit indices, and because there are concerns about how RMSEA and CFI perform with ULSMV estimation methods (Xia & Yang, 2019), it was decided to examine alternative factor structures via EFA.

Exploratory Factor Analysis

Bartlett's test of sphercity was statistically significant (X^2 (780) = 971.78, $p < .001$), which suggests that the correlation matrix was not random. The Kaiser-Meyer-Olkin statistic was .71, which is above the minimum for factor analysis. Empirical Kaiser criterion recommended retaining 10 factors and examination of the scree plot supported a five-factor solution. Consequently, the 10- , 9- , 8- , 7-, 6- , and 5-factor solutions were examined sequentially. The 10- , 9- , 8- , and 7-factor solutions were rejected because they had at least one underidentified factor with fewer than three variables with factor loadings $\geq .39$. The five- and six-factor solutions had at least three variables loading onto each factor and were examined more closely.

Communalities and factor loadings for the five-factor solution were examined to identify and potentially remove problematic items. Twenty items (Supplementary Table 1) were removed due to factor loadings < .39, communalities < .40, cross-loadings > .30, or a difference of < .20 between primary and secondary loadings (Watkins, 2018). One item *("I know how to adjust my child's insulin doses on sick days")* had a difference of .19 between primary and secondary loadings. It was decided to retain this item as it was considered theoretically relevant and the factor loading was equal to the pre-determined cutoff of .39. The EFA was re-run after each item was removed to re-examine fit with the five-factor solution. This resulted in a 20-item version of the PP-DAS that accounted for 59.92% of the variance. The same procedure was used to examine the six-factor solution. Sixteen items were removed using the same criteria, resulting in a 24-item version of the PP-DAS that accounted for 59.40% of the variance. The five- and six-factor solutions possessed similar subscales and met most criterion for adequate factors, although the internal consistency for one subscale was questionable ($\alpha < .70$) in the six-factor solution. Ultimately, it was decided to retain the five-factor solution as it was statistically equivalent or superior to the six-factor solution, and more parsimonious. The five-factor solution yielded five subscale scores: (a) Caregiver Stress, (b) Emotional Functioning, (c) Healthcare, (d) Social

Table III. *Factor Structure and Internal Consistency of the PP-DAS*

Items	PPDAS-CS ($\alpha = .74$)	PPDAS-EF ($\alpha = .82$)	PPDAS-H ($\alpha = .83$)	PPDAS-SC ($\alpha = .84$)	PPDAS-M ($\alpha = .73$)
1. I feel like the burden of T1D is completely on me.[a]	**.58**	−.05	.02	.02	−.08
2. I have a hard time trusting my spouse or partner to take care of my child's T1D.[a]	**.57**	.08	−.08	−.01	−.03
3. I have passed up career opportunities because of the responsibilities I have for managing my child's T1D.[a]	**.54**	−.07	.02	−.04	.21
4. My work performance and/or relationships have suffered because I am often absent to care for my child with T1D.[a]	**.54**	−.05	.06	−.06	.06
5. I have good methods for handling stress.	**.48**	−.04	−.06	.01	−.25
6. I have hobbies or interests that I have maintained since my child was diagnosed with T1D.	**.42**	−.08	−.09	−.08	−.06
7. I am almost always worried about my child because of T1D.[a]	.07	**−.83**	.02	.06	.07
8. I worry about my child's future because of T1D.[a]	−.02	**−.68**	.00	−.02	.02
9. I feel sad or depressed because of my child's T1D.[a]	.08	**−.83**	.04	−.02	−.06
10. I can reach someone from my child's diabetes care team when needed.	−.01	.01	**−.81**	−.03	.03
11. I am satisfied with my relationships with my child's diabetes care team (doctor, diabetes nurse/educator, dietitian, etc.).	.08	.06	**−.79**	.02	.04
12. My child's diabetes care team makes decisions about my child's diabetes care with us, not for us.	−.004	−.001	**−.77**	−.004	.004
13. I get support from relative, friends, and/or neighbors.	−.02	−.01	.01	**−.95**	.05
14. Other people in my family took time to learn about T1D.	.10	.01	.003	**−.89**	.08
15. There is at least one other person that I feel comfortable taking care of my child with T1D.	.10	.04	−.04	**−.52**	−.21
16. I have formed new relationships that are supportive of T1D.	.01	.002	.05	−.17	**−.68**
17. I dedicate time to diabetes community awareness, fundraising, or other activities for the good of other with diabetes.	.11	.13	.08	.09	**−.68**
18. Advocating for people with diabetes helps me feel that I can make something positive come of all of this.	.06	.10	−.002	.04	**−.67**
19. I can see patterns in my child's blood glucose profile that show a need for an insulin adjustment.	−.06	−.11	−.05	−.05	**−.42**
20. I know how to adjust my child's insulin doses on sick days.	−.05	−.17	−.20	−.02	**−.39**

Note. Bold indicates primary loading; PPDAS-CS = Caregiver Stress subscale; PPDAS-EF = Emotional Functioning subscale; PPDAS-H = Healthcare subscale; PPDAS-SC = Social Circle subscale; PPDAS-M = Mastery.

[a] Reverse scored.

Circle, and (e) Mastery. A second-order CFA demonstrated poor model fit (RMSEA = .08, 95% CI [.07–.09]; CFI = .83; X^2 (165) = 364.59, $p < .001$) and did not support the creation of a total score comprised of the five PP-DAS subscales. Model fit could not be improved via theoretically justifiable modification indices. Therefore, only the five subscales were calculated and use in validity analyses.

The Caregiver Stress subscale (6 items) assesses personal and professional stressors due to T1D. The Emotional Functioning subscale (3 items) assesses caregivers' psychological symptoms (e.g., worry and depression). The Healthcare subscale (3 items) concerns their child's T1D care team. The Social Circle subscale (3 items) concerns caregivers' family adjustment and social support. Finally, the Mastery subscale (5 items) relates to T1D advocacy and caregiver confidence in managing their child their child's diabetes. Internal consistencies (Table III) for the subscales ranged from acceptable (α's = .73–.74) to

Table IV. *Bivariate Correlations Demonstrating Convergent and Discriminant Validity*

	1	2	3	4	5	6	7	8	9	10
1. PPDAS-CS	–									
2. PPDAS-EF	.30***	––								
3. PPDAS-H	.17*	.11	––							
4. PPDAS-SC	.33***	.20**	.22**	––						
5. PPDAS-M	.21**	.02	.21**	.20***	––					
6. BSI-S	−.26**	−.30***	−.20**	−.05	−.06	––				
7. BSI-D	−.42***	−.30***	−.26**	−.21**	−.23**	.53***	––			
8. BSI-A	−.44***	−.39***	−.22**	−.16*	−.17*	.64***	−.75***	––		
9. PSESDM	.27***	.18*	.25**	.27***	.36***	−.12	−.36	−.34***	––	
10. DSMP-SR	.06	−.04	.07	.02	.20*	−.13	−.25	−.15	−.18*	––
11. HbA1c^{a}	−.04	−.07	−.10	.14	−.19*	.20**	.15	.16*	−.16*	−.13

Note. PPDAS-CS = Caregiver Stress Subscale; PPDAS-EF = Emotional Functioning Subscale; PPDAS-H = Healthcare Subscale; PPDAS-SC = Social Circle Subscale; PPDAS-M = Mastery; BSI-S = Somatization; BSI-D = Depression; BSI-A = Anxiety; PSESDM = Parental Self-Efficacy Scale for Diabetes Management; DSMP-SR = Diabetes Self-Management Profile, Self-Report.

^{a}HbA1c was obtained from labs or self-report if labs unavailable.

*$p < .05$; **$p < .01$; ***$p < .001$.

good (α's = .82–.84). Correlations between subscales (Table IV) were small to moderate in strength, which suggests minimal overlap. According to the Flesch–Kincaid readability statistics, the final 20-item version of the PP-DAS is written at an 8th grade reading level.

PP-DAS Descriptive Findings

Descriptive statistics for the subscales of the 20-item version of the PP-DAS are reported in Table II. Values of skew and kurtosis for the subscales were all within acceptable limits.

Convergent and Criterion

Convergent and criterion validity were examined through correlations between the PP-DAS and conceptually related variables (Table IV). All of the PP-DAS subscales were negatively correlated with the BSI Depression (r's = −.21 to −.42) and Anxiety subscales (r's = −.16 to −.44). The BSI Somatization subscale was significantly inversely associated with the Emotional Functioning ($r = -.30$, $p < .001$), Healthcare ($r = -.20$, $p = .01$), and Caregiver Stress ($r = -.26$, $p = .001$) subscales of the PP-DAS, but not the Social Circle or Mastery subscales. As hypothesized, higher total self-efficacy scores on the PSESDM were associated with all of the PP-DAS subscales (r's = .16 to .36, all p's < .05). Finally, higher scores on the Mastery subscale of the PP-DAS were associated with lower HbA1c ($r = -.19$, $p = .04$) and higher scores on the DSMP-SR ($r = .20$, $p = .01$), which provides preliminary evidence of criterion validity for the Mastery subscale. Youth HbA1c and the DSMP-SR were not significantly associated with the other PP-DAS subscales.

Discussion

Caregivers of very young children with T1D face many barriers to T1D management. As a result, these caregivers are at increased risk for poor adjustment (Streisand & Monaghan, 2014), which may exacerbate nonadherence and result in worse youth health outcomes (Pierce, Kozikowski, Lee, & Wysocki, 2017). The construct of caregiver adjustment in previous studies focused heavily on psychological functioning (Hilliard et al., 2011; Jaser et al., 2009), although our group's recent work supports a broader conceptualization of adjustment (Pierce, Aroian, et al., 2017). This article sought to describe the factor structure and initial psychometric properties of the PP-DAS, a broad measure of T1D-specific parent adjustment.

Results from the study partially support the first hypothesis, that the factor structure of the PP-DAS would mirror the five domains of caregiver adjustment (Child, Parent, Family, Social Environment, and Healthcare Community) identified by Pierce, Aroian, et al. (2017). The five subscales identified in the EFA (Caregiver Stress, Emotional Functioning, Social Circle, Healthcare, and Mastery) were not the same as social ecological framework proposed by Pierce, Aroian, et al. (2017). However, items from each of these domains were found within the subscales of the PP-DAS. The Caregiver Stress subscale included items from the Social Environment and Parent domains; the Emotional Functioning subscale included items from the Parent domain; the Social Circle subscale included items from the Social Environment domains; the Healthcare subscale included items from the Healthcare Community domain; and the Mastery subscale included items from the Child and Healthcare Community domains. Overall, the factor structure described here suggests that the PP-DAS assesses multiple dimensions of caregiver adjustment that span a social-ecological framework, although the configuration differs from the domains proposed by Pierce, Aroian, et al. (2017). This may be because specific areas of adjustment (e.g., Mastery and Caregiver Stress) are observed at multiple levels of the social-ecological framework.

Results from this study also supported the hypothesis that the initial version of the PP-DAS would demonstrate convergent validity with psychological functioning and parental self-efficacy in diabetes management. Caregivers who experience more depression and anxiety may report worse adjustment because they are less engaged in diabetes management and experience more family conflict (Mackey et al., 2014), which are measured by the Mastery, Caregiver Stress, and Social Circle subscales. Symptoms of mental health disorders in caregivers are also associated with higher HbA1c and more healthcare utilization, which may impact satisfaction with their healthcare providers and is measured by the Healthcare subscale of the PP-DAS.

Caregiver adjustment is also theorized to be related to caregiver self-efficacy in managing their child's T1D (Pierce, Kozikowski, et al., 2017). People with a sense of control over their situation and environment are more likely to adjust well (Maddux & Lewis, 1995). Therefore, caregivers who are more confident in their ability to manage their child's diabetes may also report better adjustment because of the way they act (e.g., setting realistic and concrete goals, persistence in meeting these goals), think about their situation (e.g., attending to positive information about performance, more adaptive problem-solving), and feel about challenges (e.g., feel less anxious about challenges with T1D management; Maddux & Lewis, 1995).

The PP-DAS partially demonstrated criterion validity with glycemic control and adherence. It was hypothesized that all PP-DAS subscales would be associated with adherence and HbA1c, a key diabetes clinical outcome. However, only the PP-DAS Mastery subscale was associated with HbA1c and adherence. Throughout the pediatric T1D literature, the association between glycemic control and parental adjustment, measured predominantly via psychological symptoms and parenting stress, is mixed (Hilliard et al., 2011; Jaser et al., 2009; Stallwood, 2005). Rather, caregiver adjustment may have indirect effects on glycemic control that are mediated by T1D management behaviors (e.g., self-care/adherence and problem-solving skills), as proposed by Pierce, Kozikowski, et al. (2017). Only the Mastery subscale contained items about T1D management behaviors (e.g., "I can see patterns in my child's blood glucose profile that show a need for an insulin adjustment"), which may explain why it was significantly associated with both HbA1c and adherence. Future research seeking to promote T1D health outcomes may benefit from focusing on associations between caregiver adjustment and T1D management behaviors.

This study possesses multiple strengths. First, the measure was developed through a systematic and rigorous process that included a theory-based definition of caregiver adjustment that was inducted from qualitative crowdsourcing data obtained from a relatively large, national sample of caregivers of very young children with T1D, and validated through iterative development and selection of items through stakeholder engagement. This lends strong support to the content validity of the measure. Second, the findings from the current study support a multidimensional conceptualization of caregiver adjustment, spanning domains of the social ecological framework proposed by Pierce, Aroian, et al's (2017).

Although this study possessed many strengths, the results should be interpreted in the context of some limitations. The samples for both studies were predominantly female and Caucasian, well-educated, and of moderate- to high-SES. Furthermore, there was a high amount of CGM use in the validation sample (84.7%). CGM use in very young children has potential benefits for glycemic control (Patton, Noser, Youngkin, Majidi, & Clements, 2019) and fear of hypoglycemia (Ng, Moore, Clemente, Pintus, & Soni, 2019), which may affect the experiences and stressors of these caregivers. Therefore, the clinical and sociodemographic characteristics of the samples in both studies may limit generalizability of findings to other groups. Future studies may want to replicate the procedures in study 1 to determine whether the items are applicable to other samples and include items that are important to other samples or groups. It will also be important to recruit sufficient numbers of participants from clinical and demographic subgroups to permit examination of between-group differences in the factor structure and subscale scores. The cross-sectional design of this study precluded examinations of the test–retest reliability and predictive validity of the PP-DAS. Once the randomized control trial in which the PP-DAS was developed is complete, it will be possible to examine these psychometric properties. Longitudinal studies are also needed to understand trajectories of adjustment and inform the development of interventions aimed at fostering good adjustment in caregivers. Finally, the factor structure and psychometric properties were not confirmed with a second sample, and convergent and discriminant validity were established via other self-report measures. In future studies it would be important to use multiple methods of assessment (e.g., self-report, structured interviews, and behavioral observations) to demonstrate validity. It will also be important to confirm the factor structure detailed in the current study by conducting a CFA using a different sample.

In summary, the PP-DAS appears to be a psychometrically sound instrument that measures five domains of adjustment in caregivers of very young children with T1D: Caregiver Stress, Emotional Functioning, Healthcare, Social Circle, and Mastery. The PP-DAS may present many advantages in future research examining caregivers adjustment. First, it was designed to specifically measure adjustment in caregivers of very young children with T1D, which is a growing but understudied population. Second, the PP-DAS measures adjustment more broadly so researchers can examine obtain are more comprehensive assessment of caregiver adjustment. The PP-DAS also possesses potential clinical utility. Assessments of caregiver adjustment using the PP-DAS following diagnosis and during routine clinic visits may help clinicians identify families that would benefit from additional support with specific areas of adjustment. The PP-DAS could also help clinicians monitor caregiver adjustment over time, although this would require additional studies the predictive validity of the PP-DAS and whether trajectories of caregiver adjustment can be identified.

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Supplementary Data

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

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