

Understanding the Areas and Correlates of Diabetes-Related Distress in Parents of Teens With Type 1 Diabetes

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Abstract

Objective To identify the unique areas of diabetes-related distress (DD) for parents of teens with type 1 diabetes and parent and teen characteristics associated with DD. **Methods** Areas of DD were developed from structured interviews and translated into 46 survey items. Items were analyzed with exploratory factor analysis (EFA). **Results** An EFA with 332 parents (88% mothers) reduced items to four Parent Diabetes Distress Scale (PDDS) factors (20 items, $\alpha = .94$): Personal, Teen Management, Parent/Teen Relationship, and Healthcare Team Distress. Parent DD was higher among fathers, younger or single parents, parents of teens with higher hemoglobin A1c or severe low blood glucose levels, authoritarian parenting, depressive symptoms, and low emotional support. **Conclusions** 4 areas of parent DD were identified using a newly developed measure, the PDDS. DD was associated with family demographic, teen diabetes status, and parent contextual factors, and can help identify parents who may be more vulnerable to DD.

Key words: Adolescents; diabetes; parent–adolescent communication; parent stress; parenting style; psychosocial functioning.

Raising a teen with type 1 diabetes (T1D) can be challenging and stressful. As the disagreements over independence and responsibilities grow over the teen years, parents experience many burdens and worries, including conflicts with their teens about T1D self-management and concerns about their teens' safety (especially in regards to low blood glucose levels; Streisand, Swift, Wickmark, Chen, & Holmes, 2005). A recent review found that approximately one-third of parents reported severe emotional distress at the time their child was diagnosed, and 20% reported high levels of emotional distress 1–4 years after diagnosis (Whittemore, Jaser, Chao, Jang, & Grey, 2012).

A number of studies have shown significant relationships between elevated parental emotional distress with psychosocial and health outcomes for both

parents and their children or teens with T1D (Helgeson, Becker, Escobar, & Siminerio, 2012; Jaser, Whittemore, Ambrosino, Lindemann, & Grey, 2009; Mitchell et al., 2009; Streisand et al., 2005; Whittemore et al., 2012). For example, elevated parental emotional distress among parents of children and teens with T1D has been associated with more parental depressive symptoms, lower quality of life, and greater family stress (Helgeson et al., 2012; Whittemore et al., 2012). Greater parental emotional distress has also been associated with less effective parental collaboration with their child or teen around T1D management, lower parent self-efficacy (Jaser et al., 2009; Streisand et al., 2005; Whittemore et al., 2012), and higher diabetes-specific family conflict among families with older children or teens (Williams,

Laffel, & Hood, 2009). Furthermore, there are significant linkages between high parental emotional distress and poor glycemic control among older children and teens (age range 8–17 years; Butler et al., 2008; Helgeson et al., 2012; Markowitz et al., 2012; Williams et al., 2009). Thus, elevated levels of distress are common among parents of teens with T1D, with potential negative health consequences for both parents and their teens. Relatively fewer studies have documented associations between parental emotional distress and family demographic factors. Where examined, higher levels of parent emotional distress have been associated with several family demographic factors, including being a parent of a younger child (Streisand et al., 2005; Whittemore et al., 2012), longer diabetes duration (Whittemore et al., 2012), lower family socioeconomic status (Jaser et al., 2009; Streisand et al., 2005), being a single parent (Streisand et al., 2005), and identifying as non-White (Streisand et al., 2005).

The majority of work to date on parent emotional distress encompasses a range of definitions and measures (Whittemore et al., 2012), with relatively little work focused on the stresses and burdens that parents experience specifically related to their child's diabetes, parent diabetes-related distress (DD). Two problems emerge when considering DD for parents of teens with T1D. First, it remains unclear how best to translate the documentation of DD into effective interventions. For example, little is known regarding which parent or teen demographic (e.g., age, education), personal (e.g., stressor, supports), parenting style (e.g., authoritarian), and teen diabetes status factors (e.g., hemoglobin A1c [HbA1c], severe low blood glucose levels requiring assistance) are most critical in their impact on parent DD. To address parent DD in clinical settings, it is necessary to better understand these dynamics and identify the variety of potential areas and correlates of parental DD.

Second, we are limited in our available statistically reliable and valid measure of parent DD for use in research and clinical care. Available measures almost exclusively focus on (1) global assessments of emotional distress (e.g., general life stress, quality of life; Hajos et al., 2013), (2) parenting stress measures that are not diabetes specific (e.g., Pediatric Inventory for Parents; Streisand, Branietki, Tercyak, & Kazak, 2001), or (3) measures of specific psychological symptoms (e.g., anxiety, depression, posttraumatic stress disorder) that are targeted toward symptoms rather than disease-related distress (Kroenke, Spitzer, & Williams, 2001; Radloff, 1977). While extremely valuable in their own right, none of these measures are diabetes specific, thus limiting their use as a guide to intervention. Previous literature among adults with diabetes has found DD to be conceptually distinct from global and non-diabetes-specific measures, and

to often exhibit stronger associations with behavioral outcomes and glycemic control, highlighting the need for a separate measure that is diabetes specific (Fisher, Gonzalez, & Polonsky, 2013; Fisher et al., 2010, 2015). One notable exception is the Problem Areas in Diabetes Survey–Parent Revised version (PAID-PR; Markowitz et al., 2012), a parent self-report measure based on the Problem Areas in Diabetes (PAID; Polonsky et al., 2005), a diabetes-specific scale developed for use with adults with diabetes. Unfortunately, the PAID-PR items were developed by simply rewording the original PAID items to apply to parents without follow-up validation and inclusion of parent-specific item content. Furthermore, none of the existing scales were developed specifically for use with parents of teens (vs. younger children) with T1D. Thus, some potentially critical parent areas of DD may not have been included in available measures (e.g., distress regarding relationship with teen).

The current report addressed these two interrelated problems with the following aims: (1) to develop and validate a measure that assesses DD in parents of teens with T1D, the Parent Diabetes Distress Scale (PDDS), and (2) using this measure to examine variables associated with increased parent DD to identify potential targets for intervention. We hypothesized that the development of a new scale derived directly from parents and pediatric diabetes providers would yield multiple distinct areas of parent DD, and that greater DD would be associated with parent demographics (including younger age and being female), teen diabetes status (poorer glycemic control and more severe low blood glucose levels requiring assistance), and parent contextual variables (greater general stress, fewer supports, and a parenting style characterized by more controlling and less autonomy).

Methods

Structured interviews were conducted with 20 parents of T1D teens and 7 pediatric diabetes health care providers. Recruitment for structured interviews came from referrals from health care providers at four diabetes clinics serving diverse patient samples. The sample was selected to ensure a mixed gender and age. Interviews were conducted individually. Interview questions were based on related work with adults with T1D and were reviewed by a panel of health providers and researchers before use. An example question included, "What do you find tough about raising a teen with diabetes?" Respondent descriptions of the emotional aspects of diabetes were recorded verbatim, reviewed by the authors for duplicates, and condensed into 46 specific survey items, all assessing parent DD. Parents and providers then reviewed the items for clarity and thoroughness. Response options for each

item were provided on a 5-point scale (0 = *not at all*, 1 = *a little*, 2 = *somewhat*, 3 = *a lot*, 4 = *a great deal*).

Parents of teens with T1D between the ages of 11 and 21 years, and who had been diagnosed with T1D for at least 1 year, were then invited to complete an online survey that included the 46 distress items as well as four groups of measures to assess parent and teen demographics, diabetes status, parenting style, and parent contextual variables. To recruit parents, project announcements were sent to all families with a teen diagnosed with T1D via email on the e-mailing lists of six major academic diabetes centers and diabetes Web sites known to be popular among parents. The announcement described the project and included a link to a Web site with further study information, an electronic informed consent, and the online survey. The online survey was anonymous and participation was completely voluntary. Questionnaire data were entered into a central database using a HIPAA-protected server. The research protocol was approved by ethical and independent review services, a community-based institutional review board.

Measures

Family demographic measures included parent and teen age and gender, parent education, and parent partner status (0 = not living with a partner, 1 = living with a partner). *Teen diabetes status* was assessed by number of years since diagnosis, insulin status (1 = multiple daily injections, 2 = insulin pump), parents' report of their teen's most recent HbA1c, and the number of severe low blood glucose levels in the past 6 months in which the teen required the assistance of another.

Parent stress was measured with the previously developed and tested five-item General Life Stress Scale (GLSS; Cronbach's $\alpha = .68$; Pearlman, Lieberman, Menaghan, & Mullan, 1981). The GLSS assesses the degree of stress an individual is currently experiencing in five general areas of life (finance, work, their romantic relationship, family, and health problems—modified to inquire about health problems other than diabetes), with response options ranging from 0 (*none*) to 4 (*a great deal*). The mean of the total score is calculated, with higher scores reflecting greater overall parent life stress.

Parent depression symptoms were assessed by the Patient Health Questionnaire-8 (PHQ-8; Cronbach's $\alpha = .89$; Kroenke et al., 2001), a validated and highly used eight-item scale that assesses symptoms linked to DSM-V criteria for Major Depressive Disorder. The suicide item from the PHQ-9 was omitted, which does not affect the validity of scoring thresholds or score distributions (Kroenke et al., 2001). The PHQ-8 asks how many days during the past 2 weeks the respondent experienced each of eight symptoms of depression,

with a severity score from 0 to 3 for each item (range: 0–24). The total summed score was calculated. Higher scores are indicative of greater symptoms of depression.

Parent emotional support was assessed by a five-item scale that assessed the degree of emotional support the parent received from family and friends, health care professionals, other parents of teens diagnosed with T1D, support groups, and professional organizations. Response options ranged from 0 (*none*) to 4 (*a great deal*). Although we considered the use of several previously validated social support scales, to best address the current research question we required an emotional support measure specific to the forms of support parents of teens diagnosed with T1D may benefit from. To this end we developed an emotional support measure that addresses diabetes-specific resources and supports appropriate for parents. The scale showed good internal consistency (Cronbach's $\alpha = .72$), and an exploratory factor analysis (EFA) suggested the presence of a single factor with factor loading $>.60$ for each item (range .62–.81). As expected, emotional support was significantly and negatively associated with related constructs, including GLSS ($r = -.15, p < .01$) and PHQ-8 ($r = -.29, p < .001$).

Finally, *parenting style* was assessed with the Parental Authority Questionnaire-Revised (PAQ-R; Reitman, Rhode, Hupp, & Altobello, 2002). The PAQ-R is a 30-item self-report instrument that assesses parent endorsement of various beliefs about parenting their child or teen. The current study included the *Authoritarian* (10 items, Cronbach's $\alpha = .69$) and *Authoritative* (10 items, Cronbach's $\alpha = .65$) subscales, which are scored independent of one another allowing parents to receive a score on each scale. Authoritarian parenting is described as a style that values unquestioning obedience and an attempt to control the behavior of the child, often through punitive disciplinary practices. Authoritative parenting is described as a style that is firm and clear in expectations, but flexible and rational in setting limits or making exceptions. Items were scored on a 5-point scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). The mean score across items within each subscale were calculated, with higher scores reflecting a more authoritarian or authoritative style, and lower scores not reflecting this style (Reitman, Rhode, Hupp, & Altobello, 2002).

Data Analysis

To adequately describe parent experience of DD, we first conducted an EFA with Promax rotation to determine whether the 46 parent DD items could be reduced and grouped into meaningful subscales. Based on the factor analytic results, subscales were created by averaging item responses within each subscale and

the scale total. Internal consistency of the subscales and the total scale was determined by Cronbach's α statistic. Correlations between each item and the total score were calculated with corrected item-total correlations.

To determine construct validity, Pearson correlation coefficients were generated between the PDDS scales and parent GLSS, emotional support, parent-reported teen HbA1c, and parent depression symptoms. The selection of instruments to examine construct validity was based on previous literature. Parent GLSS and depression symptoms were selected given the established moderate to high positive correlations between DD with stress and depression symptoms among adults with T1D and T2D (Fisher et al., 2015; Polonsky et al., 2005). HbA1c was included, given previous literature demonstrating a positive association between DD and glycemic control in samples of adults with T1D and T2D (Fisher, Hessler, Polonsky, & Mullan, 2012; Fisher et al., 2015), as well as its use for construct validity in the PAID-PR (Markowitz et al., 2012). Based on related support literature (La Greca et al., 1995), parent emotional support was also selected, as we hypothesized parents who received more emotional support related to their teen's diabetes, would experience lower levels of DD.

Next, to examine characteristics of parents and their teens associated with high parent DD, multiple regression analyses examined associations of the PDDS with three groups of variables: parent and teen demographics, teen diabetes status (HbA1c, insulin pump, years since diagnosis, and number of low blood glucose levels), and parent contextual variables (including emotional support, GLSS, and parenting style). A separate regression analysis was conducted for each of the three groups of variables. Parent and teen ethnicity were not included in regression models owing to the limited variability of ethnicity in the sample. Missing data were minimal (<3%) and assumed to be missing at random; missing data were not imputed.

Results

The study announcement was sent via email to approximately 540 parents on clinic registries and through select Web sites. Three hundred thirty-nine parents with a teen diagnosed with T1D started the online survey (62%), with 332 of these parents (97%) completing the survey. Parents were primarily mothers (88%), were on average 47.2 (± 5.86) years of age, and half of the sample had an education level equivalent to an undergraduate degree (average education of 16.24 years). Ninety percent were living with a partner, and 91.3% were living with their teen full-time, while the remaining parents lived with their teen part-time (see Table I). Almost all parents identified

themselves (94.9%) and their teens (92.7) as non-Hispanic White. Half of the teens with diabetes were female (50.3%). Parents reported their teens to be on average 15.3 years old (± 2.27) with T1D duration of 6.8 years (± 4.29), and 67.5% were using an insulin pump. The average, parent-reported HbA1c was 8.2% $\pm 1.5\%$ (66 mmol/mol ± 16.4 mmol/mol). Parents reported levels of general life stress and depression symptoms (6.2% reaching criterion of PHQ-8 score ≥ 15 associated with moderately severe or severe symptoms of depression) that fell within expected normal ranges (Table I). On average parents reported receiving moderate emotional support (1.78 ± 0.82). Parents reported relatively low endorsement of authoritarian parenting style and on average moderate endorsement of authoritative parenting styles within expected normal ranges (Table I).

Factor Analysis and Construct Validity of PDDS

An EFA of the 46 DD items yielded a seven-factor solution (eigenvalues ≥ 1.00) that accounted for 71.3% of the common item variance. Inspection of the scree plot of successive eigenvalues indicated that four factors might provide a good description of the data. Items that loaded $< .50$ on all factors or were cross-loaded on multiple factors (i.e., $\geq .30$) were dropped, and the remaining items were submitted to a second EFA. This analysis, with 20 items, also yielded four coherent and meaningful factors that accounted for 68.2% of the score variance. Factor loadings ranged

Table I. Parent and Teen Characteristics

Demographic characteristics	N = 332
Teen	
Age (years)	15.33 (2.27)
Gender (% female)	168 (50.3%)
Ethnicity (% non-Hispanic White)	308 (92.7%)
Years since diagnosis	6.81 (4.29)
HbA1c	
Percent	8.15 (1.50)
mmol/mol	66 (16.4)
Insulin delivery method	
Vial and syringe	44 (13.3%)
Pen	64 (19.3%)
Pump	224 (67.5%)
Number of low blood glucose levels	1.48 (2.64)
Parent	
Age	47.18 (5.86)
Gender (% female)	294 (88.6%)
Ethnicity (% non-Hispanic White)	315 (94.9%)
Education level (years)	16.24 (2.13)
Living with child full-time	303 (91.3%)
Percent married or living with partner	300 (90.4%)
Depression symptoms	5.01 (4.92)
General life stress	1.25 (0.80)
Emotional support	1.78 (0.82)
Authoritarian parenting	1.54 (1.33)
Authoritative parenting	3.08 (0.52)

from .51 to .98, and item-total correlations ranged from .51 to .82 (Table II).

Based on the item content, the four PDDS subscales were labeled as follows: *Personal Distress* centered on parents' worries about their personal quality of life, for example, "Feeling that diabetes is taking up too much of my mental and physical energy every day" (eight items, Cronbach's $\alpha = .96$); *Teen Management Distress* focused on parents' concerns about their teen's diabetes management, for example, "Worrying about my teen's low blood sugars when he/she is away from home" (six items, Cronbach's $\alpha = .88$); *Parent/Teen Relationship Distress* related to parent concerns regarding conflicts and disagreements with their teen, for example, "Feeling that my teen and I just don't work well together when it comes to diabetes" (three items, Cronbach's $\alpha = .75$); and *Healthcare Team Distress* centered on distress about the adequacy of their teen's health care, for example, "Worrying that my teen doesn't get all of the expert medical help he/she needs" (two items, $r = .75$). The total Parent Distress score, including all 20 items, also demonstrated good internal consistency (Cronbach's $\alpha = .94$).

Intercorrelations among subscales ranged from $r = .26$ to $r = .50$, suggesting related, but distinct, areas of distress. Each PDDS score was calculated as the mean of the contributing items (with scores ranging from 0 to 4.00), and the mean score per subscale for the entire sample was as follows: Personal, 1.17 (± 1.00); Teen Management, 2.12 (± 0.99); Parent/Teen Relationship, 1.49 (± 1.16); and Healthcare Team, 0.49 (± 0.89). Thus, parents reported the highest DD concerning their teen's diabetes management and the lowest DD about current health care services. The average total scale score was 1.41 (± 0.87).

The PDDS total scale and all four subscales were significantly related to the variables selected for convergent validity to suggest satisfactory validity. Greater total and subscale PDDS scores were associated with higher levels of parent depressive symptoms ($r = .22$ to $r = .55$, all $p < .001$), greater parent life stress ($r = .16$ to $r = .32$, all $p < .005$), and lower emotional support ($r = .22$ to $r = .75$, all $p < .001$). Additionally, teen HbA1c was associated with higher level of total PDDS scores ($r = .42$, $p < .001$).

The Context of Parent Distress

Family Demographics

Younger parents ($\beta = -.12$, $p < .05$; $\beta = -.14$, $p = .01$), fathers ($\beta = .13$, $p < .05$; $\beta = .15$, $p = .01$), and parents without a partner ($\beta = -.11$, $p < .05$; $\beta = -.11$, $p < .05$) were all independent predictors of higher total PDDS, and more specifically higher levels of personal distress, than older parents, mothers and partnered parents (p

values displayed for total PDDS and the Personal Distress scale respectively, also see Table III). Younger parents ($\beta = -.14$, $p < .05$) and parents of boys ($\beta = -.11$, $p = .05$) also reported experiencing significantly greater distress about their teens' management than older parents and parents of girls. Interestingly, teen age and years since diagnosis were not associated with total PDDS or any PDDS subscale score.

Teen Diabetes Status

Higher teen HbA1c ($\beta = .41$, $p < .001$) and a greater number of low blood glucose levels requiring the assistance of another ($\beta = .13$, $p < .01$) were independently associated with total PDDS. HbA1c was significantly and positively linked with parent personal distress ($\beta = .31$, $p < .001$), distress about their relationship with their teen ($\beta = .49$, $p < .001$), and distress about their teen's health care team ($\beta = .19$, $p < .001$). Number of low blood glucose levels requiring the assistance of another was positively associated with parent-reported personal distress ($\beta = .18$, $p = .001$) and distress regarding their teen's diabetes management ($\beta = .22$, $p < .001$), and parents with teens using an insulin pump reported lower distress regarding their teen's health care team ($\beta = -.15$, $p < .01$) than those using a pen or vial and syringe.

Parent Context

High authoritarian, but not authoritative, parenting strategies were significantly associated with greater total PDDS ($\beta = .22$, $p < .001$), as well as higher DD in each area with the exception of health care team distress ($\beta = .20$, $p < .001$ for Personal Distress; $\beta = .14$, $p < .01$ for Teen Management Distress; $\beta = .21$, $p < .001$ for Parent/Teen Relationship Distress). Furthermore, parents who reported less emotional support ($\beta = -.62$, $p < .001$) or greater GLSS ($\beta = .18$, $p < .001$) were both additional independent predictors of higher levels of total PDDS, as well as greater DD on each of the four specific subscales (see Table III).

Discussion

Findings from the current report identified four areas of DD for parents raising a teen living with T1D: (1) parents' own personal distress, (2) parents' distress about their teen's T1D management, (3) parents' distress about their relationship with their teen (e.g., diabetes-related disagreements), and (4) parents' distress about their teen's health care team. In contrast to previous measures, the development of the PDDS items was based on specific parent reports of their experiences parenting a teen diagnosed with T1D, leading to a fuller and more complete representation of their experienced DD. The PDDS is an internally consistent and

Table II. Exploratory Factor Analysis and Item-Total Correlations of PDDS Items

		Parent/teen relationship	Personal	Teen diabetes management	Health care team
Eigenvalue		9.47	2.14	1.40	1.27
Variance accounted for by factor (%)		47.32	10.70	7.00	6.31
PDDS items	Item-total correlation	Rotated factor loadings			
Feeling that my teen and I just don't work well together when it comes to diabetes	.715	.733	.094	-.034	.091
Feeling that I can't trust my teen to take good care of his/her diabetes	.735	.935	-.070	.014	-.035
Worrying that my teen will ignore or forget diabetes if I don't keep reminding him/her	.781	.761	.089	.136	-.036
Feeling that trying to help my teen with his/her diabetes is always a battle	.820	.870	.084	.021	-.013
Feeling that my teen doesn't do enough to manage his/her diabetes	.734	.981	-.088	-.047	-.020
Frustrated because my teen ignores my suggestions about diabetes	.781	.851	.071	-.032	.032
Feeling uncertain about how to motivate my teen to take better care of his/her diabetes	.785	.878	.053	-.007	-.011
Worrying that my nagging about diabetes is hurting my relationship with my teen	.791	.658	.224	.101	.005
Feeling unappreciated for all the ways I try to help my teen manage diabetes	.695	.344	.601	-.037	-.041
Feeling that diabetes is taking up too much of my mental and physical energy every day	.662	.059	.657	.177	.064
Feeling that no one notices that diabetes is hard on me, not just on my teen	.565	-.095	.931	.017	-.085
Worrying that others will blame me if my teen's diabetes is not well-controlled	.621	.317	.568	-.108	-.006
Frustrated by the lack of understanding and support for diabetes I get from friends and family members	.622	-.033	.774	.070	.095
Frustrated that I am the only one who takes responsibility for helping my teen manage diabetes	.667	.288	.605	-.066	.028
Worrying about my teen's low blood sugars when he/she is away from home	.562	-.031	.061	.839	-.005
Worrying that my teen will soon leave home and I cannot protect him	.545	.321	-.101	.660	-.008
Worrying about my teen's low blood sugars when he/she is sleeping	.560	-.206	.172	.817	-.029
Concerned that my teen is not prepared to deal with the world of insurance and doctors once he/she is an adult	.585	.360	-.157	.512	.063
Worrying that my teen doesn't have the right doctors for him/her	.601	.008	-.022	-.007	.942
Worrying that my teen doesn't get all of the expert medical help he/she needs	.505	-.011	.041	.004	.919

Note. Bold figures indicate factor loadings $\geq .50$ on a single factor.

valid 20-item scale that can be used in clinical and research settings as a measure of parent DD.

In line with previous reports (Markowitz et al., 2012; Whittemore et al., 2012), we find that parent DD is relatively common, with the majority of parents endorsing the presence of some DD. For example, 61.4% had a total PDDS score equivalent to at least

“a little” DD, and 25.6% had a total PDDS score equivalent to “moderate” or greater DD. Levels of parent DD were highest in regards to concerns about teen self-management, where 88.9% reported a subscale score equivalent to “a little” DD or more, and 56.9% had a total PDDS score equivalent to “moderate” or higher DD. The low to moderate

Table III. Associations Between Family Contextual Variables With Parent Distress

Family contextual variables	Total parent distress		Teen management distress		Personal distress		Parent/teen relationship distress		Health care team distress	
	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>
Parent and teen demographics										
Teen age	.05	.43	.07	.26	-.01	.80	.05	.42	.08	.21
Teen gender (female)	-.07	.19	-.11	.05	-.05	.34	-.05	.38	-.02	.64
Parent age	-.12	.04	-.14	.02	-.14	.01	-.05	.39	-.09	.13
Parent gender (female)	.13	.02	.08	.16	.15	.01	.08	.14	.05	.41
Parent partnered	-.11	.05	-.06	.24	-.11	.04	-.09	.09	-.03	.64
Parent education	-.08	.21	-.05	.32	-.08	.15	-.03	.64	-.06	.32
Teen diabetes status										
Years since diagnosis	.02	.74	.04	.49	-.08	.18	.06	.23	.01	.83
HbA1c	.41	<.001	.07	.23	.31	<.001	.49	<.001	.19	<.001
Insulin pump	-.01	.93	-.03	.56	-.01	.81	.05	.36	-.15	.009
Number of low blood glucose levels	.13	.009	.22	<.001	.18	.001	.04	.43	.03	.61
Parent contextual variables										
Parent life stress	.18	<.001	.21	<.001	.24	<.001	.10	.05	.12	.05
Parent emotional support	-.62	<.001	-.21	<.001	-.41	<.001	-.67	<.001	-.20	<.001
Authoritarian parenting	.22	<.001	.14	.007	.20	<.001	.21	<.001	.04	.49
Authoritative parenting	.04	.31	.08	.15	.05	.34	.01	.72	-.05	.32

intercorrelations among the subscales suggest that the subscales represent related but distinct areas of parent DD worthy of consideration clinically. Similar to measures of DD among adults with diabetes (Fisher et al., 2012, 2015; Polonsky et al., 2005), the PDDS was moderately associated with other life stress and negative affect constructs, including depression symptoms, emotional support, and general life stress, as well as teen HbA1c. These associations add support to the construct validity of the measure and suggest that while DD, stress, and depression symptoms are associated, they should be considered conceptually distinct.

Our findings suggest that many family demographic, parent context, and teen diabetes status characteristics are significantly associated with parent DD. Overall, the following five areas appear to be most critically related to parent DD: (1) specific parent demographics, including being a younger parent, a father, or a single parent without a partner, (2) teen diabetes management, including high HbA1c and high frequency of severe low blood glucose levels, (3) other life stressors (e.g., financial, work related), (4) authoritarian parenting style, and (5) low levels of emotional support received from friends, community, and health professionals. These findings take a needed step in identifying specific groups of parents who may be more vulnerable to experiencing high DD.

Being the caregiver of a child with a chronic illness can be challenging. Parents who experience a lack of support or stress in other areas of their lives, such as work or financial stress, may not have the emotional reserves or the time and resources to handle some of the inevitable stresses and strains that occur parenting a teen with T1D (Helgeson et al., 2012).

Importantly, this can have an interactive effect with their diabetes-specific worries, and lead to even greater stress in their personal lives and their relationship with their teen. Likewise, parents who engage in an authoritarian parenting style, characterized by a controlling and autocratic interaction style, are likely to yield few positive teen reactions, both in general and in relation to diabetes management (Anderson, 2011; Davis et al., 2001), thus leading to an increased spiral of family conflict and greater parental distress.

Additionally, aspects of teen diabetes status, such as glycemic control and frequent low blood glucose values, may also exacerbate or interact with parent and family context variables leading to high parent DD (Williams et al., 2009). Diabetes management during the teen years begins to increasingly exist outside of parents' direct control, placing parents in an especially difficult situation whereby they can feel helpless or frustrated by not being able to take more effective action when teens experience difficulties with diabetes management (Schreiner, Brow, & Philips, 2000). On the other hand, high levels of parent DD can contribute to greater stress in teens and less positive parent/teen interactions (Jaser & Grey, 2010), either of which can in turn impact teen diabetes management (Helgeson et al., 2012). While previous findings for the association between parent emotional distress and teen glycemic control have been mixed (Mitchell et al., 2009; Stallwood, 2005; Streisand et al., 2005), a more significant association occurs when the distress measure is specifically diabetes related (Markowitz et al., 2012; Polonsky et al., 2005) in contrast to the frequently used global, non-diabetes-specific measures of life stress or mental health. For example, in the current study, we

find that the level of association between non-diabetes-specific measures of general life stress ($r = .17, p < .05$) and depression symptoms ($r = .13, p < .05$) with teen HbA1c are considerably lower than the association between the DD-specific PDDS measure and HbA1c ($r = .42, p < .001$). This pattern of findings is in line with previous work with adults living with T1D and T2D in which the relationship between DD and HbA1c has been proposed to be linked in a bi-directional relationship over time (Fisher et al., 2016, 2010) and emphasizes the importance of considering DD in clinical encounters.

While causation cannot be determined, and some relationships among the variables may be reciprocal in nature, our results provide insight into some of the broad contextual characteristics that can contribute to parents feeling overwhelmed or burdened by their teens' chronic illness and, by doing so point to potential directions for intervention. Enhancing family and community emotional and instrumental support, addressing other contributing life stresses, and addressing authoritarian parenting practices may reduce parent DD and provide for more effective parenting. Acknowledging and understanding how other personal and family characteristics, as well as teen diabetes management issues, may contribute to or interact with parent DD may assist in targeting specific interventions that address specific needs—thus, creating a patient-centered approach.

The PDDS assesses parent DD across four areas that can be used clinically to identify and target specific areas for intervention. Elevated subscale scores, and in some instances elevated item scores, can provide a helpful opening to a conversation with parents about specific areas of DD and potential areas of problem solving. For example, the PDDS currently serves as an online assessment tool as part of the “Just for Parents” program (<http://justforparents.behavioral diabetes.org>), which allows parents to receive automated feedback on the areas of DD they are experiencing, view how their levels of DD compare with those of other parents of teens with T1D, and offer recommendations for how they can address or reduce their DD. Direct and informed discussions about parental emotional status are often left unaddressed in clinical settings (Fisher et al., 2013). Additionally, results point to several contextual correlates of parent DD that can be used to help identify parents who may be experiencing elevated DD, as well as consider the possible iterative role that these contextual characteristics play in their experience of DD. Our findings suggest that the unique content, prevalence and severity of DD experienced by parents, and the linkages between DD and other aspects of family context and teen status, warrant a closer examination in the ongoing care of families with a teen with T1D.

The current study has several strengths: the PDDS content is comprehensive and was derived directly from parents and pediatric diabetes providers; they were not adapted or modified from other scales. Also, the sample was community based, and a relatively comprehensive set of family, personal, and teen-related variables was included. Several limitations are noteworthy. First, given the nature of the anonymous online survey, teen HbA1c values were obtained by parent report rather than by a laboratory analysis, which could have introduced important bias. However, <3% of parents were not able to report a value or reported an improbable value, and in our related work with adults with T1D there was a high level of agreement between self-reported HbA1c and a laboratory result ($r = .84$) (Fisher et al., 2015). Second, although efforts were made to recruit a diverse group of parents, recruitment and parent report occurred online only. The number of fathers in the sample was far smaller than the number of mothers. Furthermore, the sample was primarily non-Hispanic White, college educated, from two-parent households, and more teens were reported to use pumps than the national average, thus limiting the generalizability of the findings. Third, the study was specifically designed to examine parents of teens (aged 11–21 years). Thus, the PDDS has not been validated for use with younger children. Furthermore, as data collection for the current study occurred before validation of the PAID-PR, it will be helpful for future studies to directly compare these measures to determine the degree of overlap and unique areas of application for each measure. Last, as the data are cross-sectional, the direction of associations cannot be determined, nor can we present test–retest data or the degree of sensitivity to change for the PDDS in this initial report. Future work should be conducted to replicate the PDDS factor structure and collect test–retest data with another sample of parents that is designed to allow for linkages with electronic medical records for further validation.

DD is common among parents of teens diagnosed with T1D and is linked with parent psychosocial variables (depressive symptoms, emotional support), parenting style, and teen glycemic control and number of low blood sugar episodes. Results of the current study suggest promising psychometric properties for the PDDS, including good internal consistency and construct validity. The PDDS can be used in both clinical and research settings to assess areas of DD. Many areas of personal, family and parenting contexts are significantly associated with parent DD and may need to be addressed in clinical care to enhance parent well-being, improve parenting style, and boost teen diabetes management.

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