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Parental diabetes distress is a stronger predictor of child HbA1c than diabetes device use in school-age children with type 1 diabetes

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ABSTRACT

Introduction Diabetes distress (DD) describes the unrelenting emotional and behavioral challenges of living with, and caring for someone living with, type 1 diabetes (T1D). We investigated associations between parent-reported and child-reported DD, T1D device use, and child glycated hemoglobin (HbA1c) in 157 families of school-age children.

Research design and methods Parents completed the Parent Problem Areas in Diabetes-Child (PPAID-C) and children completed the Problem Areas in Diabetes-Child (PAID-C) to assess for DD levels. Parents also completed a demographic form where they reported current insulin pump or continuous glucose monitor (CGM) use (ie, user/non-user). We measured child HbA1c using a valid home kit and central laboratory. We used correlations and linear regression for our analyses.

Results Children were 49% boys and 77.1% non-Hispanic white (child age (mean±SD)=10.2±1.5 years, T1D duration=3.8±2.4 years, HbA1c=7.96±1.62%). Most parents self-identified as mothers (89%) and as married (78%). Parents' mean PPAID-C score was 51.83±16.79 (range: 16–96) and children's mean PAID-C score was 31.59±12.39 (range: 11–66). Higher child HbA1c correlated with non-pump users (r=−0.16, p<0.05), higher PPAID-C scores (r=0.36, p<0.001) and higher PAID-C scores (r=0.24, p<0.001), but there was no association between child HbA1c and CGM use. A regression model predicting child HbA1c based on demographic variables, pump use, and parent-reported and child-reported DD suggested parents' PPAID-C score was the strongest predictor of child HbA1c.

Conclusions Our analyses suggest parent DD is a strong predictor of child HbA1c and is another modifiable treatment target for lowering child HbA1c.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Diabetes distress is common in families of school-age children with type 1 diabetes, and previous studies have linked diabetes distress to higher glycemic levels in children.

WHAT THIS STUDY ADDS

⇒ In a large cross-sectional study, parents' diabetes distress level was a stronger predictor of concurrent child glycemic levels than child distress, child insulin pump use, and demographic variables.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Diabetes care teams should consider screening for diabetes distress in families of school-age children with type 1 diabetes, as treating parent distress may be another pathway toward reducing child glycemic levels.

INTRODUCTION

Youth living with type 1 diabetes (T1D) and their families must engage in a rigorous daily treatment regimen to achieve near-normal glucose levels, which is important in preventing the onset of long-term diabetes complications, such as neuropathy and retinopathy.[1] Research suggests that maintaining a glycated hemoglobin (HbA1c) level less than 7.0% can reduce the risk of microvascular complications to levels comparable with persons without T1D.[2] Moreover, there is evidence that achieving an HbA1c level less than 7.0% can be safe for youth with T1D provided they do not also have a history of severe hypoglycemia or extensive comorbid conditions.[3 4] Unfortunately, recent data from the Type 1 Diabetes Exchange also suggest that only 17% of youth meet their HbA1c target.[5]

To help youth to achieve a lower HbA1c level, research supports the efficacy of adding an insulin pump and/or continuous glucose monitor (CGM) to daily T1D management. Specifically, epidemiological data show that use of either of these devices associates with a lower HbA1c level when compared with non-users.[5] As another modifiable target to help youth achieve a lower HbA1c, it may help to address emotional burdens parents and children may carry related to living with T1D.[6 7]

For families of school-age children with T1D, guidelines recommend that parents and children share daily T1D management behaviors and that responsibility for specific management behaviors should be based on the youth's level of T1D knowledge, skill, autonomy, and general maturity.[1] However, this recommendation may increase the risk that parents and school-age children experience feelings of diabetes distress (DD). DD is a multisymptom emotional condition distinct from depressive disorders and focused on the emotional and behavioral challenges of living with diabetes or caring for someone who is living with diabetes.[8] Symptoms of DD can include sadness, fear, grief, and anger related to any aspect of living with diabetes. In persons experiencing more extreme symptoms, it can also express itself as burnout and make it hard to keep up with daily diabetes management.[8–10]

In families of school-age children living with T1D, research suggests that DD is common and positively associated with child HbA1c levels.[9] There is also emerging evidence that it is possible to reduce parents' report of DD using cognitive–behavioral therapy techniques, potentially making DD a modifiable target to lower child HbA1c levels.[11 12] Presently, it is unknown if levels of parent and child DD associate with T1D device use in school-age children. However, because insulin pumps make it possible to administer more flexible and accurate insulin doses and CGM enables youth and parents to monitor glucose levels throughout the day, view trends in glucose levels, and receive alarms for any extreme out of range values without the necessity of painful finger sticks, it is possible that T1D device use may associate with lower DD levels. On the other hand, it is possible that T1D device use may associate with higher DD levels if parents and children perceive the amount of data and information about T1D available through insulin pumps and CGM overwhelming, and/or children perceive wearing a device on their body as undesirable. To date, there are also no studies exploring how parent and child DD levels and child T1D device use relate to child HbA1c levels in a single model. Therefore, this study sought to explore these two questions in a large sample of families of school-age children living with T1D. Based on the potential to titrate insulin and glucose levels more closely using either an insulin pump or CGM, we hypothesized that T1D device use (either pump or CGM) would correlate with lower levels of parent and child DD in families of school-age children. We also hypothesized that when explored in the same model, both DD (parent and child) and child T1D device use would explain significant variance in child HbA1c levels.

METHODS

Participants and procedures

We recruited parents and children aged 8–12 years old at two pediatric diabetes clinics in the Southeast and Midwestern regions of the USA to participate in a study relating parent and child DD to child glycemic levels and treatment engagement (Remedy to Diabetes Distress, R01 DK127493).[13]

Eligible families had a child with a T1D diagnosis, who was between 8 and 12 years old, used intensive insulin therapy (insulin pump or multiple daily injections), and spoke English. Families excluded from the study had children on combination regular and neutral protamine Hagedorn insulin therapy, children with an allergy or extreme sensitivity to the adhesive and/or skin preparation used for CGM, and children with a comorbid renal disease.

Parents provided verbal informed consent and permission for their child to participate. Children ≥7 years old also provided verbal assent to participate. We collected child HbA1c levels and parent and child survey responses during either an in-person or remote study visit. We targeted parents who self-identified as playing a major role in their child's daily T1D treatment. We compensated parents and children US$20 for participation.

Measures

Demographics

Parents used an electronic survey to report all demographic information and to indicate if their child used an insulin pump or CGM in their daily diabetes treatment. Demographic data included parent and child age, child sex, parent and child race/ethnicity, duration of T1D, parent marital status, parent relation to the child, and family income.

Hemoglobin A1c

All children completed a validated finger-stick home HbA1c kit concurrent to completing the study surveys.[14] We provided a prepaid and addressed box for families to mail their study kits to a central laboratory for analysis using automated high-performance liquid chromatography (reference range 4.0-6.0% (20–42 mmol/mol); Tosoh Corporation, San Francisco, California, USA).[15]

Parent Problem Areas in Diabetes-Child

Parents reported on their levels of diabetes distress using the Parent Problem Areas in Diabetes-Child (PPAID-C). This is a 16-item measure validated for use in parents of school-age children with T1D.[9] Parents respond to items on the PPAID-C using a 6-point Likert scale (1=not a problem–6=big/serious problem). We scored parents' PPAID-C surveys to yield a total score (range: 16–96) with higher scores reflecting higher levels of distress (Cronbach's alpha for the current sample=0.93).

Problem Areas in Diabetes-Child

Children reported on their levels of diabetes distress using the Problem Areas in Diabetes-Child (PAID-C). This is an 11-item measure validated for use in school-age children (8–12 years old) with T1D.[9] Children respond to items on the PAID-C using a 6-point Likert scale (1=not a problem–6=big/serious problem). We scored children's PAID-C surveys to yield a total score (range: 11–66) with

higher scores reflecting higher levels of distress (Cronbach's alpha for the current sample=0.89).

Statistical analysis

We used SPSS V.27 to conduct all study analyses. Descriptive statistics included frequencies, percentages, means, and SDs of our demographic and outcome variables. We ran Pearson correlations to examine relations between the PPAID-C, PAID-C, and children's HbA1c level and point biserial correlations to examine relations between children's device use and each of the continuous variables to test our first hypothesis. To test our second hypothesis, we used linear regression models to examine the variance accounted for in child HbA1c based on device use (ie, pump and/or CGM), PPAID-C, and PAID-C scores, while controlling for family socioeconomic status (SES) and T1D duration. We used an alpha of p<0.05 to signify statistical significance.

RESULTS

Sample characteristics

The analyzed sample included 157 parent–child dyads. Children had a mean age of 10.2±1.5 years, mean T1D duration of 3.8±2.4 years, and a mean HbA1c of 7.97±1.64%. There were 77 (49%) boys and 80 girls (51%) in the sample. For parents, mean age was 40.13±6.25 years, 89% self-identified as the child's mother and 78% identified as married. Parents also reported race and ethnicity for themselves and their child. Overall, 77.1% of parents identified their family as white, 9.6% black or African American, 6.4% Hispanic or Latinx, 3.8% more than one race, 1.3% Asian, and 1.3% Native American or American Indian. One parent preferred not to identify their race/ethnicity. Parents self-reported their highest grade in school completed and current employment status/job title, which were used to calculate a Hollingshead Four-Factor Index Score for dyads.[16] This was used as the study's primary measure of family SES.

Measures and outcomes descriptives

Parents' mean PPAID-C score was 51.83±16.79 and children's mean PAID-C score was 31.59±12.39, suggesting that both parents and children perceived DD as a 'medium problem' for them. Among children, 106 (67.5%) were current insulin pump users and 111 (70.7%) were current CGM users.

Simple correlations

Children's HbA1c levels positively correlated with parents' mean PPAID-C (r=0.35, p<0.001) and children's PAID-C scores (r=0.24, p<0.001) and negatively correlated with family SES (r=−0.20, p<0.05) (table 1). We also observed a positive correlation between parents' mean PPAID-C scores and children's mean PAID-C scores (r=0.56, p<0.001). We observed a negative correlation between children's pump use and HbA1c (r=−0.16, p<0.05) suggesting a tendency for children using a pump to have lower HbA1c levels. We also observed a positive correlation between children's pump use and T1D duration (r=0.27, p<0.001) suggesting a tendency for children using a pump to have had longer duration of T1D at the time of the study. There were no significant correlations between children's CGM use and HbA1c level or between children's device use and parents' PPAID-C score and children's PAID-C score. However, because there was no correlation between children's CGM use and HbA1c level, we did not include CGM use in subsequent analyses.

Regression models

To examine the second hypothesis, we entered the control variables (T1D duration and family SES), children's pump use (yes/no), parents' PPAID-C score, and children's PAID-C scores into a model predicting children's HbA1c level. The full model produced a significant result ($F_{5, 150}$=6.667, p=0.000) and explained 18.2% of the variance in children's HbA1c levels. Parents' PPAID-C scores (4.8%) showed the strongest association with children's

Table 1 Pearson correlations

	Child HbA1c	Child age	Child T1D duration	Family SES	Child CGM use	Child pump use	PAID-C	PPAID-C
Child HbA1c	1	0.018	0.116	0.204*	-0.121	-0.159*	0.239**	0.355**
Child age		1	0.139	0.029	0.025	0.181	-0.047	-0.014
Child T1D duration			1	0.034	-0.051	0.266**	0.020	0.029
Family SES				1	0.062	0.116	-0.063	-0.253**
Child CGM use					1	-0.148	0.058	0.000
Child pump use						1	-0.044	-0.051
PAID-C							1	0.563**
PPAID-C								1

*P<0.05, **p<0.01.
CGM, continuous glucose monitor; HbA1c, glycated hemoglobin; PAID-C, Problem Areas in Diabetes-Child; PPAID-C, Parent Problem Areas in Diabetes-Child; SES, socioeconomic status; T1D, type 1 diabetes.

Table 2 Full regression model

	Unstandardized coefficients				
	β	SE	Standardized coefficients (β)	t-value	P value
Family SES	-0.017	0.012	-0.114	-1.478	0.141
T1D duration	0.106	0.052	0.155	2.024	0.045
Pump use (y/n)	-0.591	0.270	-0.169	-2.192	0.030
PAID-C	0.009	0.012	0.066	0.736	0.463
PPAID-C	0.027	0.009	0.275	2.973	0.003

Constant=7.101 (p=0.000); F value=6.667 (p=0.000); R^2=0.182 (p value same as F value).
PAID-C, Problem Areas in Diabetes-Child; PPAID-C, Parent Problem Areas in Diabetes-Child; SES, socioeconomic status; T1D, type 1 diabetes.

HbA1c, explaining almost twice the variance in HbA1c as the other predictor variables. Children's pump use explained 2.3% of the variance in child HbA1c, while children's T1D duration explained 2.2% of its variance. Interpreting the unstandardized coefficients, our data would suggest every 1-year reduction in T1D duration associated with a 0.1% decrease in children's HbA1c, every 10-point decrease in parents' PPAID-C score associated with a 0.3% decrease in children's HbA1c level, and pump use associated with a 0.6% decrease in children's HbA1c level (table 2).

DISCUSSION

DD is common among families of school-age children living with T1D and is related to children's HbA1c.[9] In a large sample, we aimed to explore how parent and child DD correlated with children's T1D device use (ie, CGM and insulin pump) and how these variables associated with children's HbA1c levels. Contrary to hypothesis one, we found no correlation between parent and child DD and children's current use of an insulin pump or CGM. However, our correlations did replicate previous findings demonstrating positive associations between parent and child DD and children's HbA1c[9] as well as previous results demonstrating a negative association between family SES and children's HbA1c levels.[17] We also found that children who used insulin pumps had significantly lower HbA1c levels than those who did not. We did not observe a correlation between children's CGM use and HbA1c, which was unexpected. As noted previously, there are epidemiological data suggesting lower HbA1c among CGM users than non-users.[5] Moreover, a recent clinical trial found a 0.37% reduction in HbA1c among adolescents randomized to use CGM compared with adolescents randomized to use a glucometer.[18] It is possible we did not find an association between children's CGM use and HbA1c because our sample was predominantly comprised of CGM users and therefore lacked adequate variability to detect an association with HbA1c.

Our second hypothesis was that parent and child DD and children's T1D device use (CGM and insulin pump) would each explain variance in children's HbA1c levels. We found partial support for this hypothesis. As noted previously, because there was no association between children's CGM use and their HbA1c level, we did not move forward in testing a model that included children's CGM use; this result did not support our second hypothesis. However, our full model including parent and child DD, children's pump use, and control variables suggested that parent DD, children's pump use, and children's T1D duration together explained 18.2% of the variance in children's HbA1c level, thereby partially supporting this hypothesis. An interpretation of the unstandardized beta weights suggested that every 10-point decrease in parents' DD associated with a 0.3% decrease in children's HbA1c (β=0.03, p=0.003). We believe this is noteworthy because regulatory authorities like the Food and Drug Administration have in the past noted that in clinical trials, a change of 0.3% or greater in HbA1c level is clinically meaningful.[19] Moreover, parents' DD is modifiable with cognitive–behavioral therapy,[11 12] making it possible that teaching parents strategies to help reduce their feelings of distress may also help children achieve a lower HbA1c. It is also noteworthy our results replicate previous findings which have linked pump use to lower HbA1c levels in youth.[20–22] Helping families who would like to start an insulin pump obtain a pump may also represent a modifiable behavior to enable youth to achieve a lower HbA1c.

Although we anticipated our predictor variables would account for unique variance in children's HbA1c, we did not anticipate that parent PPAID-C scores would show the strongest association with children's HbA1c. We were also surprised that child PAID-C scores had the weakest association. One explanation for these findings may be due to child age. By restricting recruitment to families of school-age children 8–12 years old, it is possible that we recruited a sample of families where parents bore the majority of T1D management responsibility,[1] thus lessening the impact child DD has on diabetes control. It is possible that in a sample that included more adolescents, we might see a stronger association between child DD and their HbA1c. As a limitation of our full model, it is important to note that we only explained 18.2% of the variance in children's HbA1c. This suggests that there

may be other variables we did not include in our model that associate with children's HbA1c (eg, treatment engagement, healthcare utilization, exercise, shared responsibility for T1D management) which should be studied in the future.[23–25]

Current standards of care offered by the American Diabetes Association suggests clinics should begin to regularly screen for DD in families of children beginning at 7–8 years old.[1] Within the current literature, there are several relatively short, validated surveys of DD for use in children,[9] teenagers,[26] and parents[27] which may enable clinics to conduct these types of screening. In our sample, parents' and children's mean DD scores were comparable with levels previously reported.[9] Notably, children's mean HbA1c (7.95±1.64%) suggested our sample was relatively tightly controlled and may support the general recommendation to screen all children and their caregiver for DD versus just children with HbA1c above clinical targets.

We recognize a few study limitations that may impact the generalizability of our findings. First, we acknowledge the lack of racial and ethnic diversity of the sample. There is increasing evidence of enduring health, social, and economic inequities in the USA on child glycemic levels and evidence these inequities could associate with parent-reported and child-reported DD levels.[28] In the future, it will be important to retest our model in a sample of families of more diverse racial and ethnic backgrounds. Second, our parents were predominantly mothers, leaving an open question as to whether fathers' or other caregivers' DD also more strongly associates with child HbA1c than current pump use. Third, while most of the youth in our sample used an insulin pump (67.5%), we did not record the number of children on a hybrid closed-loop pump versus an open system. In the future, it may be helpful to retest our model and to distinguish between children using MDI, an open pump, and a hybrid closed-loop pump. Fourth, we acknowledge the possibility that children could have under-reported DD levels due to social desirability, which might explain why the PAID-C score was not a significant predictor in our regression model. However, we note that our mean PAID-C score is comparable with another published score,[9] which may help support its reliability. Fifth, we recognize that our study focuses on a relatively narrow age range (8–12 years old) of children and their parents, and therefore encourage future studies to test our model in families with either younger or older children with T1D. Lastly, our study design is cross-sectional, preventing us from examining the stability of our associations across time. Strengths of this study include its relatively large size, use of validated measures of parent and child DD, use of a central laboratory to analyze the HbA1c samples collected via a validated home kit, and the decision to control for family SES and T1D duration in the regression model.

In conclusion, this study is the first to examine the association between diabetes device use and parent and child report of DD in families of school-age children with T1D. It is clinically noteworthy that our study shows that school-age children and their parents report moderate levels of DD even if the child's HbA1c level reflects relatively tight glycemic control.[9] It is also clinically noteworthy that our full regression model found parent DD to be the strongest predictor of child HbA1c even after controlling for child DD, current pump use, T1D duration, and family SES. Because parent DD is potentially treatable,[11 12] it is possible teaching parents strategies to help them manage their DD may be one pathway toward improving diabetes control and family quality of life. Future studies should evaluate quality of life as an outcome within these models and should aim to retest our model in a sample that includes more fathers and other caregivers, families from more diverse racial and ethnic backgrounds, families that include children from a broader age range, and takes into consideration advanced insulin delivery systems.

What are the new findings?

⇒ In this large, cross-sectional, longitudinal study, parents and children described diabetes distress as a medium problem.
⇒ Parent report of distress was a stronger predictor of concurrent child glycemic levels than child distress levels, child insulin pump use, and demographic variables.
⇒ Because diabetes distress is potentially treatable, our findings highlight a new target for future clinical intervention for these families of school-age children.

Contributors SRP wrote the manuscript, designed the research study and secured funding. NK, JSP, LAF, MB and MAC assisted with study execution and provided feedback on the manuscript. SRP is the guarantor of this work and, as such, had full access to the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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Competing interests MAC receives consulting fees from Glooko and has research support from Dexcom and Abbott Diabetes Care that is unrelated to this project. LAF receives material research support from Dexcom which is not related to this project.

Patient consent for publication Not required.

Ethics approval This study involves human participants. The Institutional Review Board (IRB) at Children's Mercy Hospital & Clinics approved this study (IRB# STUDY00001502) prior to recruitment and all study procedures. The study operated under a SMART IRB agreement with Nemours Children's Health in a reliance role. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request.

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