

# Characterizing Diabetes Distress in Adolescents with Type 1 Diabetes

Viena T. Cao, Sahar S. Eshtehardi, Barbara J. Anderson, & Marisa E. Hilliard

Baylor  
College of  
Medicine



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## OBJECTIVES

- Expectations for increasing diabetes management autonomy in adolescence can lead to diabetes distress.
- Higher T1D distress is linked to suboptimal glycemic outcomes.
- Identifying what teens find most burdensome about T1D may help care teams address the most relevant issues.

## METHODS

- Participants: n=135 teens (age 12-17) with T1D.
- Baseline data from 2 intervention studies.
- Problem Areas in Diabetes - Teen Scale.<sup>1</sup>
  - 26 items
  - Responses of 5-6 on 6-point scale represent a “serious problem.”
- Tabulated frequency of items rated 5-6 and calculated correlations with HbA1c.

## RESULTS

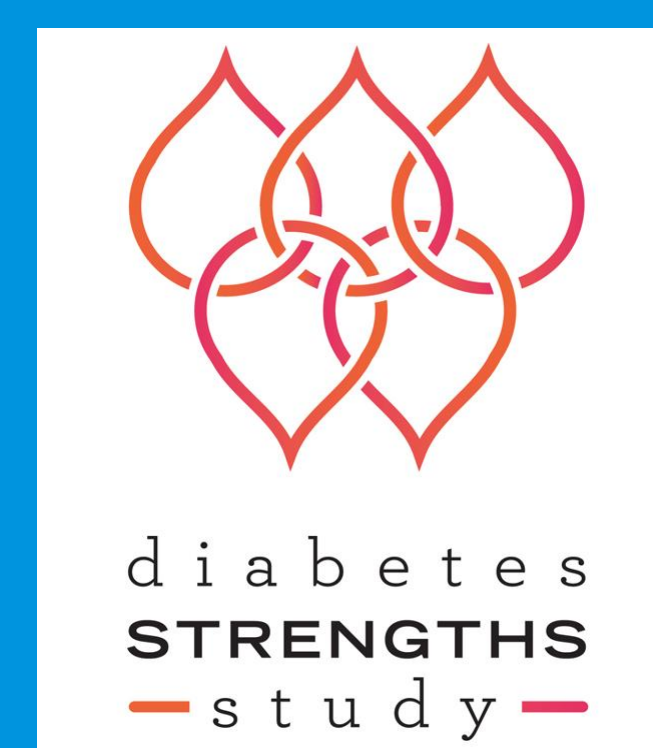
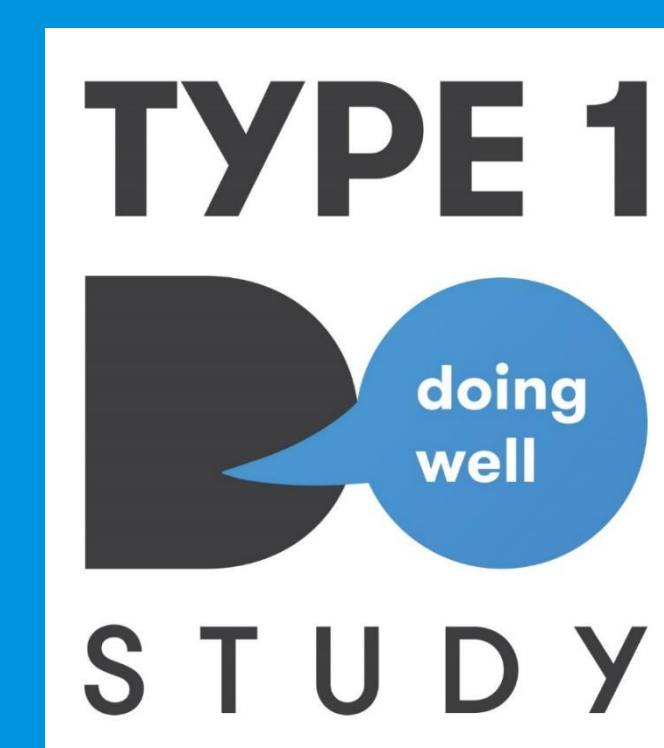
- Refer to Tables 1 and 2 for participant characteristics and detailed results.
- Top 5 items teens endorsed as a “serious problem”:
  1. Friends/family do not understand difficulty of diabetes (24.4%).
  2. Friends/family act like “diabetes police” (23%).
  3. Worry about future/complications (20%).
  4. Interference with having fun with friends (20%).
  5. Feel “burned out” (19.4%).

## CONCLUSION

- In our racially/ethnically diverse sample, over 10% of teens endorsed a wide range of issues (20 of 26 items) as very distressing.
- At least 20% identified social issues and concerns about complications as causing serious distress.
- However, few items correlated with HbA1c, suggesting the need for evaluation of relevant health outcomes, beyond glycemic indicators.

The *diabetes issues* that teens with T1D endorsed as the *most distressing* were *not necessarily the ones linked to glycemic outcomes.*

Addressing each teen's most pressing concerns may *reduce self-management barriers and improve T1D-related quality of life outcomes.*



Poster and abstract: <http://bit.ly/T1Dteendistress>

Twitter: @RADLab\_T1D

Inquiries: Marisa Hilliard, PhD at [marisa.hilliard@bcm.edu](mailto:marisa.hilliard@bcm.edu)

## DATA/TABLES

Table 1. Participant Characteristics

Characteristics (n=135)	%(n) or Mean±SD
Age, years	15.1±1.6
Gender, % female	57% (77)
Race/Ethnicity	
Non-Hispanic, White	59% (79)
Non-Hispanic, Black	13% (18)
Non-Hispanic, Other	7% (10)
Hispanic	21% (28)
Insulin regimen-pump, %	73% (98)
CGM users, %	24% (32)
Hemoglobin A1c, %	8.7±1.7

Table 2. Most Frequently Endorsed PAID-T<sup>1</sup> Items (>10% reported “serious problem”)

Item	%
Others do not understand difficulty of diabetes.	24.4
Others act like “diabetes police.”	23.0
Worry about future/complications.	20.0
Interference with having fun with friends.	20.0
Feel “burned-out.”	19.4
Worry about weight.	19.3
Feel upset about diabetes not on track.	16.3
<b>Feel I'm failing with diabetes.*</b>	<b>15.7</b>
Parents don't trust me.	14.1
Little motivation.	13.3
Striving for perfection.	13.3
<b>Blood sugars seem uncontrollable.**</b>	<b>13.3</b>
Feel blamed for blood sugars.	13.3
Feel overwhelmed by diabetes.	12.6
<b>Miss/skip blood sugar checks.*</b>	<b>12.6</b>
Feel discouraged by highs.	11.2
Diabetes management away from home.	11.1
Parents worry about complications.	11.1
Worry about lows during exercise.	10.6
Cannot control my eating.	10.4

Significant correlations with HbA1c (\*p<.05, \*\*p<.01) in bold.

<sup>1</sup>Weissberg-Benchell J, Antisdel-Lomaglio J. Diabetes-specific emotional distress among adolescents: feasibility, reliability, and validity of the problem areas in diabetes-teen version. *Pediatr Diabetes* 2011;12:341-344.

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**Authors:** Viena T. Cao, BS<sup>1</sup>, Sahar S. Eshtehardi, MS<sup>1</sup>, Barbara J. Anderson, PhD<sup>1</sup>, Marisa E. Hilliard, PhD<sup>1</sup>

<sup>1</sup> Baylor College of Medicine and Texas Children's Hospital

**Objective:** Adolescents are often expected to take on more autonomy in their T1D management, which can increase diabetes distress. Overall, elevated distress is linked to suboptimal glycemic outcomes. Characterizing the aspects of diabetes distress that teens report as most difficult may help care teams address the most relevant psychosocial concerns during this challenging developmental stage.

**Methods:** We analyzed baseline data from 2 behavioral interventions, totaling 135 adolescents (age 12-17) with T1D (M age=15.1±1.6, 57% female, 59% non-Hispanic White, M HbA1c=8.7±1.9). Youth completed the Problem Areas in Diabetes Teen scale, a measure of diabetes distress where teens rate how much each of 26 items is a problem for them (6-point scale, 5-6 represent a "serious problem"). We extracted HbA1c from the electronic medical record.

**Results:** The table presents the frequency with which teen rated each item as "serious problem" and significant correlations with HbA1c.

**Conclusion:** A wide range of issues (20 of 26 items) were endorsed by ≥10% of teens as very distressing. At least 20% identified social issues and concerns about possible complications as serious problems. Items significantly linked to HbA1c were not necessarily those that teens found most distressing. Addressing teens' most pressing concerns may help them feel understood, reduce self-management barriers, and ultimately improve quality of life and health.

Frequency of items endorsed as “serious problem” and significant correlations with HbA1c		
Item	% endorsing as “serious problem”	<i>r</i>
Friends/family do not understand difficulty of diabetes.	24.4	
Friends/family act like “diabetes police”.	23.0	
Worry about future/complications.	20.0	
Interference with having fun with friends.	20.0	
Feel “burned-out”.	19.4	
Worry about weight.	19.3	
Feel upset about diabetes not on track.	16.3	
Feel I’m failing with diabetes.	15.7	0.218*
Parents don’t trust me.	14.1	
Little motivation.	13.3	
Striving for perfection.	13.3	
Blood sugars seem uncontrollable.	13.3	0.262**
Feel blamed for blood sugars.	13.3	
Feel overwhelmed by diabetes.	12.6	
Miss/skip blood sugar checks.	12.6	0.181*
Feel discouraged by highs.	11.2	
Diabetes management away from home.	11.1	
Parents worry about complications.	11.1	
Worry about lows during exercise.	10.6	
Cannot control my eating.	10.4	
Unsure what/how much to do.	9.7	
Anger about diabetes.	8.9	
Concern about food/eating.	8.9	
Not checking blood sugars often enough.	8.1	
Sadness about diabetes.	5.9	
Unsure if mood related to blood sugars.	4.5	

\*p<0.05, \*\*p<0.01