



Diabetes Distress Perceptions, Experiences, and Diabetes Education Preferences in Adults with T1D

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T1D Exchange

Background

- Diabetes distress (DD) is common in adults with type 1 diabetes (T1D),^{1,2,3} yet it is unclear from current research how people with T1D understand and experience DD in their own words.
- Educational interventions can decrease DD in teens and adolescents, but research in adults with T1D is limited.^{4,5}
- Diabetes educators may be in a unique position to help alleviate DD, but there is a knowledge gap between diabetes education services and preferences for these services in adults living with T1D.

Primary Objectives

In adults with T1D, we aimed to:

- Assess lay understanding of 'diabetes distress'
- Describe experiences with diabetes distress
- Explore experiences with and perceptions of education about diabetes distress.

Methods

- Participants from the T1D Exchange Registry were invited to an online survey if they were (1) diagnosed with type 1 diabetes, (2) aged 18 years or older, and (3) Living in the US or US territory.
- Participants (N=272) enrolled and reported their knowledge and personal definition of DD, then reviewed a standard definition and reported their DD experiences and educational preferences.
- Measures included the 2-item Diabetes Distress Screener (DDS-2)⁶ and Powerlessness and Physician Distress subscales of the T1D Diabetes Distress Scale (T1-DDS)¹.

Participant Characteristics

Total N=272		
	Mean	SD
Age	45.1	14.6
Time since diagnoses (years)	24.4	16.0
Gender	N	%
Male	65	23.9%
Female	201	73.9%
Non-binary/genderqueer	3	1.1%
Prefer to self-identify [Please Specify]	3	1.1%
Transgender History – Yes	3	1.1%
Race – White	255	93.8%
Ethnicity – Hispanic	9	3.3%
CGM Use	259	95.2%
Pump Use	214	78.7%
Most Recent Self-Reported HbA1c ^a	N	%
≤ 7%	231	85.9%
> 7%	38	14.1%

Note. ^aHbA1c was missing for n = 3 participants.

Results

Categories	N	%
Accurate ^a	1	0.3%
Partially accurate ^b	219	80.5%
Not Accurate ^c	29	10.7%
Does Not Know	23	8.5%

Answers were coded based on the degree of alignment with 4 domains of DD described in the DDS-17 (Regimen, Emotional Burden, Interpersonal, Physician). ^aAccurate responses included all 4 domains. ^bPartial responses included 1 to 3 domains. Not Accurate^c responses did not mention any domains.

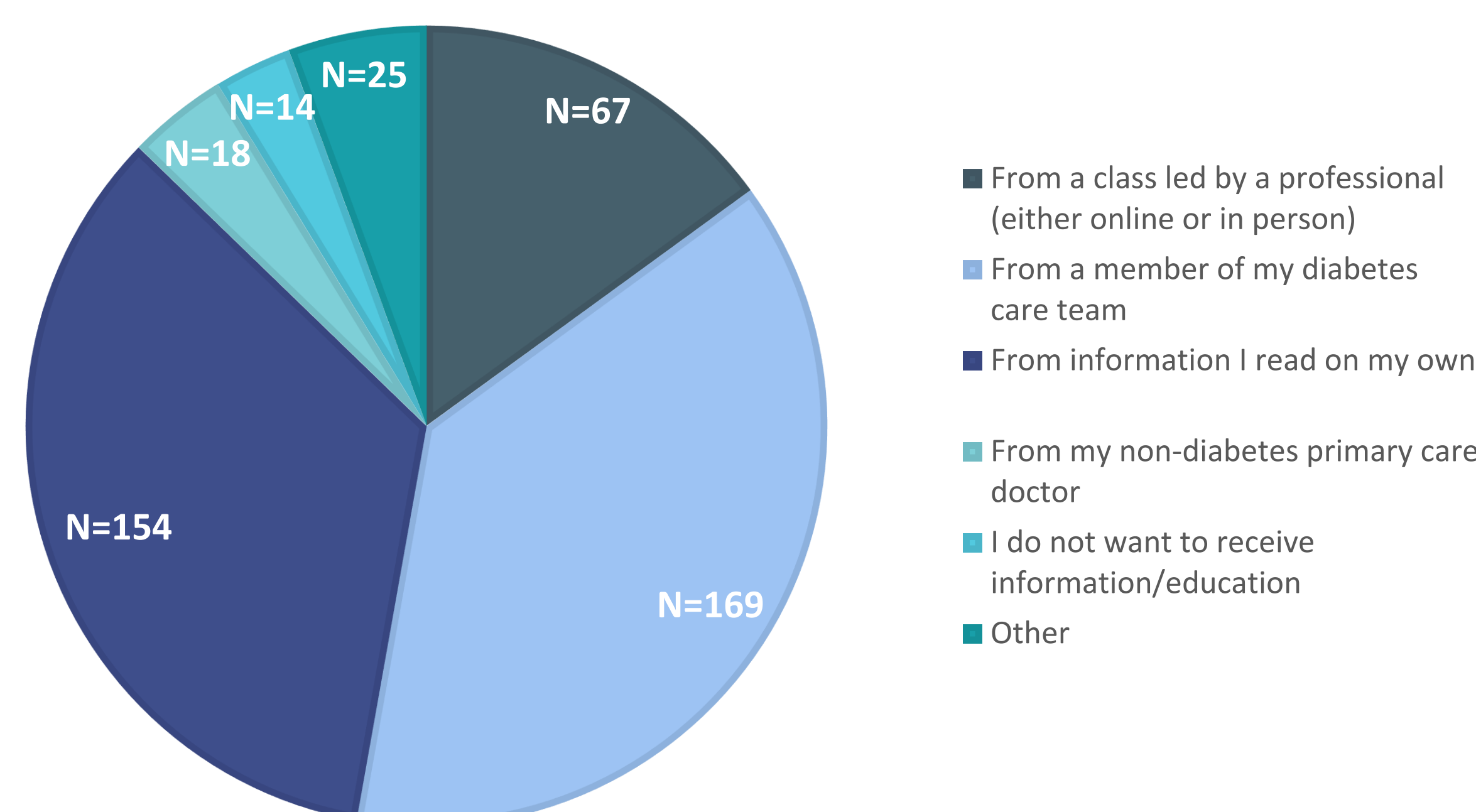
Experiences with Diabetes Distress

When asked if they have experienced DD in the last 12 months, 88.6% of the sampled reported they had.

A total of 75.7% were not familiar with the concept of DD (somewhat familiar or less).

Few reported their healthcare team discussed DD with them (15.7%) to some extent or more. Endocrinologists were the most common providers reported to have discussed DD.

DD Education and Information Preferences



Descriptives of measures of diabetes distress

	Mean (SD)
DDS-2 - Total	2.8 (1.2)
Feeling overwhelmed by the demands of living with diabetes.	3.0 (1.3)
Feeling that I am often failing with my diabetes regimen.	2.7 (1.3)
Powerlessness (T1-DDS) – Total	3.1 (1.2)
Feeling discouraged when I see high blood glucose numbers that I can't explain.	3.3 (1.4)
Feeling that there is too much diabetes equipment and stuff I must always have with me.	2.7 (1.4)
Feeling worried that I will develop serious long-term complications, no matter how hard I try.	3.4 (1.6)
Feeling that I've got to be perfect with my diabetes management.	3.0 (1.5)
Feeling that no matter how hard I try with my diabetes, it will never be good enough.	3.0 (1.6)
Physician Distress (T1-DDS) - Total	2.0 (1.3)
Feeling that I can't tell my diabetes healthcare team what is really on my mind.	1.9 (1.3)
Feeling that I don't get help I really need from my diabetes healthcare team about managing diabetes.	2.1 (1.6)
Feeling that my diabetes healthcare team doesn't really understand what it's like to have diabetes.	2.2 (1.6)
Feeling that my diabetes healthcare team doesn't know enough about diabetes and diabetes care.	1.8 (1.5)

The number of participants experiencing 'moderate' or higher distress differed depending on the measure used.

DDS-2
44.9%
n = 122

Powerlessness Subscale
75.4%
n = 205

Physician Subscale
32.4%
n = 88

Key Takeaways

- Most participants reported they were not familiar with the concept of diabetes distress (75.7%) and most (80.5%) reported only a partially accurate definition in their own words.
- Moderate diabetes distress (44.9%) and T1D-related powerlessness (75.4%) were common experiences, despite most participants (85.9%) meeting ADA recommendations for HbA1c (7.0% or less).
- Few participants reported their healthcare team discussed DD with them (15.7%) to some extent or more.

Conclusions & Limitations

Conclusions

- Most of the sample had limited familiarity with the meaning of DD prior to the study, which suggests there is a lack of familiarity with how to discuss DD among adults with T1D.
- Most participants reported their healthcare team had not discussed DD with them extensively. Yet, many participants had recent or current experiences with DD. There may be a lack of engagement about DD from providers in ways that resonate with their patients.
- Diabetes educators are in a unique position to help educate adults with T1D about DD and to provide clinical care to ease management-related burdens.

Limitations

- Our sample was largely non-Hispanic, White females, and most were CGM and pump users. Over two thirds of the sample met adult ADA targets for HbA1c (HbA1c ≤ 7.0%). Therefore, these results may not be generalizable.

References & Acknowledgements

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