

Understanding Dual Perspectives: Burnout and Adherence in Adolescents with T1D

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BACKGROUND

- ❖ Type 1 diabetes mellitus (T1D) is the second most prevalent chronic illness in pediatric populations, with rates increasing annually across the USA
- ❖ Glycemic control is least optimal in adolescents with T1D, due to puberty-related biological changes and increasing psychosocial independence
- ❖ The majority of young adults (>18 yo) report burnout related to their T1D management; burnout in adolescents remains unexplored

OBJECTIVE

- ❖ Investigate the perspectives of adolescents with T1D regarding their self-reported insulin adherence and feelings of burnout, and compare these perspectives with those of their parents/guardians

METHODS

- ❖ Qualitative design utilizing semi-structured, 1:1 interviews with adolescents with T1D and, separately, their parents/guardians to explore emerging themes and sub-themes
- ❖ Participants were recruited via Stanford Pediatric Endocrinology's emailing list
- ❖ Inclusion criteria:
 - Adolescents ages 11-17 yo with T1D for >12 months
 - Adolescent living with parent/guardian who is also willing to be interviewed
 - All participants fluent in English
- ❖ Data collection:
 - Interviews were conducted between September–November 2024
 - Interviews were audio & video recorded and transcribed using Zoom. Coding was reviewed with peers prior to final analysis
 - Subject pairs received a \$50 gift card
- ❖ Study approved by Stanford University IRB

RESULTS

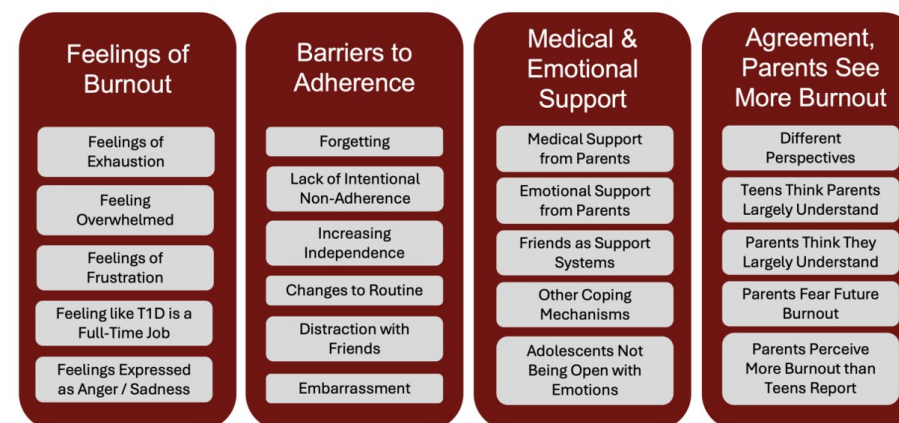


Table 1: Identified Themes and Exemplars

Theme 1 Feelings of Burnout

Adolescents with T1D may experience feelings of burnout

"Some days it's just, it's so much. And it's **exhausting**. And I don't want to deal with it anymore" - 15F

"Sometimes I'm, like, **sad and frustrated**." - 13F

"I think his emotions are usually outward, it's not as often 'poor me.' It is, but not like sobbing, crying. It's often 'poor me' **angry**, slamming things around. So if that's a **lack of control**, then maybe. I don't think he has the words for it yet... He's so **frustrated and burntout** that [he has low blood glucose levels] and it's not his fault" - mom of 17M

Theme 3 Medical and Emotional Support

Adolescents generally feel they have medical and emotional support

"My **friends** would like check in on me and be like 'hey, do you need anything' and they were like sitting with me, and it was nice to know in that moment I couldn't do it all myself, but I had people who were there to help me" - 15F

"I had 2 lows last night, and my **mom helped me** by waking me up because I did not wake up. And so, yeah. And this morning I was very tired, and I was telling her how I was tired from the lows, and she was just like **comforting me**" - 16F

"We [mom and dad] are her **safety net**" - mom of 13F

- ❖ Data saturation was reached after 16 participants (8 pairs) were interviewed. Ongoing interviews were conducted to ensure a robust sample
- ❖ Thematic analysis was used to identify themes, sub-themes, and link exemplars (Table 1)
- ❖ Four major themes were identified: 1) feelings of burnout, 2) barriers to adherence, 3) medical and emotional support, and 4) general agreement between adolescents and parents, although parents perceived more burnout than what adolescents report

Theme 2 Barriers to Adherence

Adherence is impacted by forgetfulness, lack of routine, and increasing independence

"I feel like it's mainly when I'm not at home because when I'm at home I have like a **schedule**, and when I'm away like traveling, or whatever. It's kind of hard to remember" - 16F

"Probably like the alarms going off in school ... when the alarms go off it's like loud sometimes, so **everyone just turns around** and wonders what that is" - 13M

"It's **forgetting** to bolus honestly. It's like, you know, you hang out with your **friends** or you whatever, and it's like you just forget that. Oops, you went high [blood glucose]." - mom of 14nonbinary

Theme 4 Agreement, Parents See More Burnout

Adolescents and parents generally agree, although parents may perceive more burnout that adolescents report

"I think [my mom] knows that I have [negative emotions] because I talk to her about that" - 16F

"When school first started, I used to like keep **forgetting** to dose for my food cause like I was trying to like, finish my food, because the lunch was like way shorter than it was in elementary school, and I would like forget" - 11F

"The first like two weeks of school, she was not dosing for lunch, and it was not something she was telling us... You know her not dosing was a symptom of maybe like **burnout**" - mom of 11F

Post-Hoc Overarching Theme

Although adolescents with T1D and their parents generally agree that some non-adherence and symptoms of burnout are present, each adolescent and adolescent-parent pair represents a unique situation with variance in both severity of symptoms and their mutual understanding.

DISCUSSION

- ❖ This study illustrates diabetes burnout among adolescents with T1D, which is often linked to cognitive and emotional barriers as well as environmental and routine barriers.
- ❖ While both adolescents and parents agree on the existence of burnout, parents tend to perceive more burnout and express concerns about future burnout, indicating a potential communication gap.
- ❖ Additionally, adolescent-parent pairs appear to represent unique situations, underscoring the complexity of family dynamics surrounding T1D.
- ❖ Limitations:
 - Overrepresentation of patients and parents from a single institution and region may limit generalizability to broader populations and experiences.
 - Due to study design, unable to disentangle differences stratified by age, duration of T1D, and level of involvement in T1D management.

CONCLUSION

- ❖ This study highlights some of the challenges adolescents with T1D face, while also elucidating perspectives of parental understanding.
- ❖ Although parents and adolescents largely agree that non-adherence and diabetes burnout are present, parents tend to perceive more burnout symptoms.
- ❖ As patient-parent pairs appear unique, tailored interventions addressing individual and family perspectives to improve T1D management and support are needed.
- ❖ As the incidence of T1D continues to rise, providers should prioritize screening for and addressing diabetes burnout in adolescents to optimize care, considering both mental health and glycemic control.