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Diabetes Distress in Emerging Adulthood: Content Validity of the Problem Areas in Diabetes—Emerging Adult Version (PAID-EA) Using Qualitative Analysis

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Abstract

Purpose: The purpose of this study was to explore the emotional work of diabetes during emerging adulthood and to explicate the validity of a newly developed measure of diabetes distress (DD) for use with emerging adults living with type 1 diabetes mellitus (T1DM), the Problem Areas in Diabetes—Emerging Adult version (PAID-EA).

Methods: Young people ages 18 to 30 with T1DM were recruited online to complete a cross-sectional survey including measures of DD, depressive symptomology, and the PAID-EA. To evaluate content validity, 2 open-ended questions asked what was the most significant emotion or worry discussed in the survey items and what feelings were missed in those items. Responses were analyzed using directed qualitative content analysis.

Results: A total of 254 (87%) participants responded to at least 1 of the 2 open-ended questions. Three themes and 1 subtheme were identified: (1) fear of the future with the subtheme of worry about the cost of diabetes, (2) acute worries about living with diabetes, and (3) challenges with finding support. More PAID-EA items corresponded with these themes than items on the original Problem Areas in Diabetes or Center for Epidemiologic Studies Depression Scale, supporting the validity of the PAID-EA and clarifying the developmental-stage-specific aspects of DD.

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Declaration of Conflicting Interests

The authors declare that there is no conflict of interest.

Authors' Note

Portions of preliminary qualitative analyses are described in the first author's doctoral dissertation²⁰ and the initial psychometric validation of the PAID-EA.¹⁹ Portions of preliminary qualitative analyses of 1 specific item on the PAID-EA was an oral abstract presentation at the American Diabetes Association Scientific Sessions in June 2022 and are described in a brief report currently under review.

Conclusions: Emerging adulthood is a period in which the future should hold infinite possibility, but young people with T1DM describe a staggering fear of the future with markedly limited possibilities, supporting the need to measure the developmental-stage-specific experience of DD as captured on the PAID-EA.

The developmental stage of emerging adulthood is an extended period of role experimentation from ages 18 to 30 that is characterized by many competing demands, including educational, social, and economic upheaval.¹ This is a time of transition in all parts of life as adolescents graduate from high school and move on to college, a first full-time job, or military service. Many emerging adults move away from their childhood homes with varying degrees of support from their families and begin to transition toward financial independence. Changing social supports are common, where now friends and romantic partners play a larger role in peoples' lives than their families of origin. This period is uniquely challenging for young people living with chronic disease, such as type 1 diabetes mellitus (T1DM).²⁻⁴

Emerging adults with T1DM experience the highest average A1C across the life span⁵ as well as significant psychosocial challenges⁶⁻⁸ and are at risk of adverse outcomes.^{9,10} Emotional distress from the burden of managing diabetes, referred to as diabetes distress (DD), is essentially universal among people with T1DM and can have a significant impact on day-to-day life.¹¹ DD encompasses the negative emotions that result from living with T1DM and includes feeling overwhelmed, worried, and frustrated.¹² T1DM management in emerging adulthood is something of a perfect storm, wherein the circumstances of this developmental stage can escalate DD, which in turn impacts glycemic control, which can then also worsen DD.¹³⁻¹⁵

Arnett¹⁶ originally described the developmental stage of emerging adulthood as brimming with optimism; it is the time where people feel that many futures are possible. However, research suggests this may not be the case for emerging adults living with T1DM.^{7,17} Thus, the purpose of this qualitative analysis was to explore the emotional work of diabetes during emerging adulthood and to explicate the validity of a newly developed measure of DD for use with emerging adults living with T1DM, the Problem Areas in Diabetes—Emerging Adult version (PAID-EA). The PAID-EA was developed, refined, and validated¹⁸⁻²⁰ to incorporate and acknowledge the effect of life stage on the experience of DD in emerging adults, similar to measures developed for children,^{21,22} adolescents,²³ parents of youth with T1D,^{21,24,25} and adults.^{26,27} Thus, this analysis aimed to explore the content validity of the PAID-EA in this developmental context as described by emerging adults living with T1DM and to examine and confirm that all aspects of DD were represented by the items on the PAID-EA.

Methods

Design

To address study objectives, a cross-sectional, online survey methodology was employed because recruitment occurred entirely during the COVID-19 pandemic. This article presents a qualitative analysis of open-ended questions at the end of the online survey.

Setting

Three online recruitment approaches were undertaken. First, the College Diabetes Network, a 501c3 nonprofit company whose mission is to improve the lives of young adults living with T1DM, posted about study recruitment on its social media accounts. Second, multiple emerging adult social media influencers in the diabetes online community were recruited to post on Instagram about life with T1DM, with approved recruitment language appearing in the comments.²⁸ These influencers received \$20. Lastly, to ensure adequate representation of men, the Diabetes Education and Camping Association listserv shared recruitment language with staff and alumni targeting young men by email. Recruitment lasted for 3 months. Inclusion criteria were that participants must be 18–30 years old, have T1DM, be able to read and write English, and provide consent to participate. All participants had the opportunity to enter a raffle for 1 of 5 \$100 Amazon gift cards. All phases of this project were approved by the Institutional Review Board at Boston College before any study procedures commenced.

Online Survey

The online survey included demographic (age, gender, race, Hispanic ethnicity, student status, health insurance status) and clinical questions (age at diagnosis, insulin pump use, continuous glucose monitor use, A1C). Because this sample was recruited during the COVID-19 pandemic, 1 question assessed the severity of the impact of the pandemic on the participant's life, and 1 question asked if the pandemic had affected their mood.

Measures

The first measure in the online survey was the original Problem Areas in Diabetes (PAID), which includes 20 items about the emotional burden of living with diabetes.²⁶ Higher scores indicate more DD. Next in the survey was the newly developed and refined PAID-EA.^{18–20} The refined 25-item PAID-EA, with 5-point Likert-type response options scored as 0 to 4, reflects the emotional burden of living with T1DM specific to the developmental stage of emerging adulthood. Higher scores indicate more DD. The final measure was the Center for Epidemiologic Studies Depression Scale (CES-D), a 20-item self-report assessment of depressive symptomatology.²⁹ Higher scores indicate greater frequency of depressive symptoms. The original PAID and the CES-D were used to confirm construct validity as part of the psychometric validation of the PAID-EA, and this analysis is reported elsewhere.¹⁹

Qualitative Data

The open-ended questions that followed were, “Of all the emotions, worries, and feelings related to living with diabetes that were asked about in the above questions, which one is the most important or significant to you? Your insights are very important to help us better understand young adults' experience with diabetes.” The second follow-up question was, “Are there any emotions, worries, or feelings related to living with diabetes as a young adult that we missed in our questions?”

Data Analysis

Preliminary analyses of these 2 open-ended questions revealed extensive descriptions about life with T1DM²⁰ and necessitated examination using a rigorous qualitative approach. Therefore in this analysis, these 2 open-ended questions were analyzed using directed qualitative content analysis.³⁰ In the first step of analysis, the responses were read by 2 authors (KW and RV) experienced in diabetes clinical care, education, and support particularly focused on this age group. To ensure validity and trustworthiness, the authors bracketed their experiences by journaling, and thorough field notes were kept throughout the analysis. First, the manifest messages were coded independently and then together, which were then compared and discussed. Then the codes were placed into categories and subcategories, which were organized into themes. Frequency counts of the codes aided in identifying themes. The first question had 3 themes with 1 subtheme. The second question's themes were organized in response to the themes found in the first question and compared to items on the surveys.

Content Validity

Although content validity was addressed in the development and revision of the PAID-EA through the use of expert opinions and cognitive interviews with the target population,^{18–20} frequent and repeated exploration of content validity during the validation process ensures a measure captures the many facets of the construct it intends to measure.^{31,32} So, to further evaluate content validity using qualitative analysis, the categories and themes identified in the 2 open-ended questions were continuously compared and contrasted to items in the PAID, the PAID-EA, and the CES-D.

Results

Participant Characteristics

The entire study sample consisted of 287 emerging adults with T1DM, however, this analysis included only the 254 participants who responded to at least 1 of the open-ended questions (see Table 1). Participants had a median age of 24 years (range 18–30). Two hundred one participants identified as women (79%), 50 (20%) identified as men, and 3 (1%) identified their gender in another way. Although 229 (90%) identified as White, 25 (10%) identified with another race, either exclusively or in addition to White, and 26 (10%) identified as being of Hispanic ethnicity. Many in the sample were students, with 109 (43%) full-time students and 18 (7.1%) part-time students. Additionally, reflecting the health care transitions that occur during this life stage, 119 (47%) had their own health insurance, 131 (52%) remained on their parents' health insurance, and 4 (1.6%) were uninsured. A substantial proportion of the sample had access to advanced diabetes technologies: 198 (78%) wore an insulin pump, and 228 (90%) used a continuous glucose monitor in the last month. Given the relatively high diabetes device use in this sample, it is not unexpected that the sample had a mean self-reported A1C of $7.1\% \pm 1.2\%$ with a range of 4.9% to 11.4%. Data collection was completed during the COVID-19 pandemic; 170 (67%) participants reported that the pandemic had a moderate or severe impact on their life, and 177 (70%) reported their mood was worse than prior to the pandemic.

Open-Ended Responses

For the open-ended questions, 250 (87%) participants responded to the question about the most significant emotion or worry, and 212 (74%) responded to the question regarding what emotion or worry was missed (208 of whom also responded to the first question). There were 33 (13%) participants who did not respond to either question; these nonresponders had a median age of 23 (18–30), 23 (70%) identified as women, had a median diabetes duration of 11 (1–21) years, and had a mean self-reported A1C of $7.2\% \pm 1.2\%$ with a similar frequency of device use.

Question 1: The Most Meaningful Items

For the emerging adult participants, diabetes appeared to be a roadblock in front of the feeling of limitless possibilities that is typical of this developmental stage. This analysis revealed that for emerging adults living with T1DM, the most meaningful challenges mentioned in the survey represented feelings of fear—fear for the future as well as more immediate worries about life with diabetes. To potentially mitigate these fears, they sought support from others during the many transitions of this stage. Although the life trajectory during emerging adulthood is certainly heterogeneous, these results suggest that emerging adults with T1DM are at particular risk of a more challenging transition to adulthood, mostly related to life with diabetes during this stage. The participants reported feeling that their diabetes was holding them back from having a typical experience as an emerging adult. They were aware of a world of infinite possibility that their peers were experiencing, but diabetes presented a barrier that did not allow them to participate fully.

Theme 1: Fear of the Future

The largest primary theme was a fear of the future, which encompassed a general unspecified fear and specific fears, such as a fear of complications in the future, worries about pregnancy and having children in the future, concerns about how diabetes would affect their future career, and even worries about death. This fear reflected the developmental-stage-specific increase in concrete future thinking in emerging adulthood, where young people begin to imagine and plan for their future in a way that they did not in adolescence. Participants described a rather crippling worry about what their lives may look like in the future due to the burden of diabetes:

The most lingering worries for me are thinking about the future; the pressure to obtain and keep health insurance, the pressure to keep good blood sugar control to fend off complications, and the uncertainty of how T1DM might affect me in my future life in ways that I haven't even thought about yet. (Female, age 23)

This fear was not only of the known bogeymen but also of things they may not have even imagined yet. This fear impacted every aspect of their lives, including career and family planning:

I always personally feel scared when thinking about diabetes in my goals, future, life. I am scared to have kids because I don't want to give it to them. I'm afraid that I will not be a successful teacher because of my diabetes. (Male, age 20)

As participants were conceptualizing their futures, there was always the worry that diabetes would get in the way and prevent them from achieving their dreams. Their futures were not filled with optimism and limitless possibilities. Instead, they were consumed by fear and worry about both concrete things in their lives right now and hypothetical outcomes in the future.

Subtheme: Worry About the Cost of Diabetes

The most frequently cited fear of the future, and the most frequent code overall, was related to the worry about the cost of diabetes and obtaining insurance. Participants described challenges in the process of becoming financially independent during this life stage and navigating health care for the first time, with the start of their own full-time employment and the looming prospect of the loss of access to their parents' insurance at age 26. In fact, some participants expressed that this worry was so large it was hard to experience any other worry:

Cost. Everything else is secondary. (Female, age 28)

Many participants identified this subtheme of cost and insurance coverage as a hypothetical fear about the future, and these concerns about cost touched on many important decisions and life choices arising during emerging adulthood, such as finding a career and becoming financially independent from their family of origin:

Worrying about the cost of diabetes constantly—that worry affects my career path because I want to be able to have good insurance and be able to afford my medication, makes me feel guilty that I can not [*sic*] afford my supplies right now without the help from family. (Female, age 23)

While many participants cited this as a hypothetical fear, some participants reported experiences of being unable to afford diabetes care. Several participants reported that those experiences had impacted their career choices. These participants perceived diabetes as limiting their options, and thus, they were unable to participate in the world of limitless possibilities that is a hallmark of emerging adulthood:

Cost of management. T1D forces me to remain in an industry I do not fully enjoy. I would like to pursue graduate school. However, I experienced being uninsured as an undergraduate. I don't want to relive those experiences. (Male, age 30)

Theme 2: Acute Worries About Living With Diabetes

The second theme focused on acute worries and emotions related to the present experience of managing diabetes, including worries about lows and highs, feelings of burnout and exhaustion, feeling not good enough or like a failure, and striving for perfectionism. This theme represented the multiple emotional facets of day-to-day life with diabetes, likely experienced in similar ways across the life span. Many participants described having diabetes-related burnout, constantly striving to meet unobtainable and unrealistic goals that may feel arbitrary. Although many of these emotions were not specific to emerging adults, these worries appeared to limit the emerging adults' ability to engage fully in all of the possibilities of this developmental stage:

Sometimes it's hard looking at the big picture of life knowing all that entails for diabetics, all the injections, site changes, finger sticks, doctors appointments, the highs and the lows. It can be daunting when life should be exciting for someone my age. Instead of thinking about how I can live my life to the fullest I have to think about how I can live my life to the fullest yet being cautious and making sure I'm able to afford all my supplies, having my doctors appointments on time it's all just very overwhelming. (Female, age 19)

The daily management of diabetes is overwhelming for people of all ages; however, during emerging adulthood, a young person becomes fully independent with the many disparate tasks of diabetes management for the first time. Participants identified that this was often experienced as overwhelming and exhausting:

Managing diabetes and other chronic illnesses is just exhausting. It feels like there aren't enough hours in the day to take care of myself bc [*sic*] it feels like a full time job. It is hard to take care of yourself when you are so tired from taking care of yourself. (Female, age 23)

When faced with entirely independent management of diabetes, participants felt the burden of this unending work. This led to feelings of burnout, exhaustion, and feeling overwhelmed.

Theme 3: Challenges With Finding Support

The third theme was around the challenges of finding support and positive relationships during the many transitions of emerging adulthood. This theme included feeling alone while wanting to feel understood, developing and sustaining supportive romantic relationships, coping with judgment from others, and worrying about the need for help when considering living alone. Many participants expressed that they did not have enough support from family and friends and at the same time felt guilty for burdening their loved ones with diabetes-related needs. Because this developmental stage is characterized by disrupted social connections with frequent changes in living situations and geography, it appeared that social support concerns were rather salient to these participants:

The one that is most significant to me right now is having to deal with living alone with diabetes. I will be living alone very soon and it worries me as to how I might handle it when my blood sugar is high or low. I've always taken comfort in knowing that a parent or a significant other is around to help, so this will be a change of pace and it is definitely unsettling considering I deal with some pre-existing anxiety. (Female, age 27)

During these developmentally appropriate transitions and changes, emerging adults with T1DM also struggled with finding support and feeling safe. Diabetes seemed to get in the way of relationships and impacted how participants viewed themselves:

Feeling like I can't do what other people my age can do and that when I need help I'm a burden on my family and friends. That I'm not lovable or good enough. (Female, age 19)

As they navigated emerging adulthood with its frequent changes in social support, many participants reported feeling uncomfortable disclosing their diabetes to new people, which

undermined their ability to receive support when they needed it in the setting of frequently changing social environments:

Telling people about it [diabetes] (as in how/when to mention to new people - personally I'd rather never tell but that doesn't always seem right either). (Female, age 23)

Despite the impact of diabetes on many different types of relationships, participants identified that having someone who understands their diabetes can make them feel less alone and isolated. Participants who did not have friends with diabetes felt even more isolated and disconnected:

Isolation issues. As common as T1DM is I don't have any friends like me. (Female, age 23)

Emerging adulthood is the stage when many young people find others who seem to understand them, both in platonic friendships and intimate relationships, potentially as long-term partners. These participants reported that social support was even more important to them because of their diabetes, but also, many reported that their diabetes seemed to interfere with their ability to make friends and that they were hesitant to disclose their diagnosis. This experience underscored the challenges of inconsistent social support during emerging adulthood for young people with T1D.

Question 2: What Was Missed

The second question asked about survey omissions related to emotions or worries regarding living with T1D as an emerging adult. Forty-two participants (17% of all participants) left the response space blank. Out of the 212 responses to this question, the majority of participants revealed the survey was comprehensive: 108 (51%) participants specifically wrote that nothing was missed. However, another 104 (49%) participants responded to this question with important aspects of their life with diabetes that they felt were not represented in the prior items. These responses can be categorized into 2 themes: topics that were included in the prior questions and topics that were omitted, representing both potentially universal experiences and individual experiences.

Theme 1: Topics Included

Some of the concepts that participants detected as missing were actually represented in the survey questions. Multiple participants identified challenges with diabetes cost, diabetes affecting their career plans, worries about having children, struggling with perfection, and the challenges of having to manage diabetes on their own. Although there were items that addressed these topics, participants likely felt that their experiences with those issues were not fully articulated in the survey. For example:

Just being alone doing everything yourself. (Female, age 18; corresponds to PAID-EA item 15: "I feel overwhelmed about having to do diabetes all by myself.")

Wanting to be perfect, but I always come up short. It feels like a constant failure as a diabetic. (Female, age 18; corresponds to PAID-EA item 11: "I feel that I must be perfect in my diabetes management.")

This apparent overlap of the answers to this open-ended question with the survey items raised 2 potentially disparate ideas. First, these responses supported and provided evidence of the content validity of the PAID-EA. However, these responses also raised potential concerns regarding whether the wording of a question was unclear or the intended topic was not understood by the participant. Upon significant and extended reflection by the authors, it appeared that these themes likely felt bigger to the respondents than could be captured in a single item on the surveys. Therefore, the participants needed to express the weight of these emotions and worries in the open-ended question because of the immensity of the burden perceived by the participants. The authors concluded this was not a threat to content validity, but rather an expression of the burden of diabetes being bigger and weightier than can be expressed in brief and simple items on a survey.

Theme 2: Topics Omitted

Of the 2 categories of perceived missed topics, the first category consisted of universal experiences not mentioned in prior questions. Given the recognition that diabetes impacts nearly all aspects of daily life, there were several concerns that participants reported as missing from the survey. These included diabetes concerns while driving, the challenges of managing exercise, and the physical burden of always carrying diabetes supplies. Participants felt that their concerns about diabetes while doing these everyday activities set them apart from their peers without diabetes:

Sometimes when I'm driving, I find myself worrying about my blood sugar which is not something a typical young adult has to worry about. (Female, age 18)

Perhaps exercise. I get really frustrated when I try to exercise and my diabetes holds me back. Even something as simple as walking the dog can plummet my blood sugar and I feel like I'm kissing [*sic*] out and not being as healthy as I could be without diabetes. (Female, age 30)

It is important to note that another universal concern that a few participants identified related to health insurance worries:

I think more questions about financial situations would be good. I am afraid for when I am off my parents [*sic*] insurance and I honestly don't know how I will pay for supplies. I will probably have to forgo pumps and dexcoms to pay for anything. (Female, age 21)

Interestingly, it appears that many participants attributed their worries regarding health insurance to the worry about cost as articulated in Item 21 ("I worry about the cost of diabetes") despite the fact this item did not specifically address insurance.

Finally, some of the concepts that participants felt were missing were topics that were very specific to their individual experiences of diabetes related to other aspects of their health and identity. These topics represented significant factors that can modify the emotional burden of diabetes, such as concurrent physical and mental health comorbidities, disordered eating behaviors, and systemic racism. Some participants identified these topics as important and felt that their experiences were not represented in the prior questions:

Also, I have two other autoimmune diseases. They heavily impact my diabetes. So I'm not just part of the T1D community. But the larger invisible illness community. (Female, age 25)

Connection of T1D to mental illness. I have bipolar disorder and the diabetes really impacts it and visa versa [*sic*]. (Female, age 26)

Another big issue for me is body image. When I was diagnosed I was super tiny because I was [in] DKA, and then with the weight gain although it was healthy I have a terrible body image of myself which sometimes causes me to skip insulin to loose [*sic*] weight. I know it's not healthy but it's so hard to loose [*sic*] weight as a diabetic I just felt like it was my only option. (Female, age 19)

Every young adult living with diabetes isn't White [*sic*]. So my experience varies significantly than that of my White [*sic*] peers due to dealing with the impact of systemic racism as well. (Female, age 28)

Some of these topics were more related to diabetes (eg, autoimmune disease and disordered eating), whereas others were not diabetes-specific (bipolar disease and systemic racism). Participants felt that the intersectionality of their diabetes and other life challenges made the experience of emerging adulthood particularly challenging. There may be numerous other person-specific experiences omitted from the survey, but it is notable that most participants did not provide such examples.

Content Validity

Each survey item and the theme to which it corresponded are displayed in Table 2. The number of survey items corresponding to each theme ranges from 1 to 10 for the PAID-EA, from 0 to 5 for the PAID, and from 0 to 5 for the CES-D. In fact, for all of the diabetes-related challenges that the participants highlighted as most important, there were more PAID-EA items that corresponded with the theme than corresponded to items on the PAID or CES-D. For the subtheme of “worry about the cost of diabetes,” which was the most frequent code in this analysis, only the PAID-EA had an item that addressed this issue (Item 21).

Discussion

Emerging adults living with T1DM appear to carry a substantial emotional burden of living with diabetes that may prevent them from participating fully in the world of limitless possibilities that is characteristic of this developmental stage. In particular, the frustrations, worries, and feelings related to living with diabetes are especially weighty in this life stage. Importantly, these results support the content validity of the PAID-EA because it appears to capture much of this emotional burden.

This analysis was informative because almost all participants responded to 2 open-ended questions online, providing robust depth and detail. Response rates to open-ended questions can be extremely variable, from few to a majority of respondents.^{33–35} These analyses suggest that participants felt these items were especially relevant and meaningful to them and therefore were compelled to share a great deal of details of their life with

diabetes; the literature suggests that respondents are more likely to complete open-ended questions on topics in which they are interested.³⁶ Importantly, participants identified many developmental-stage-specific issues that were captured only on the PAID-EA, and although some PAID items do correspond to themes identified here, most of those are related to acute worries of living with diabetes that likely are common across the life span.

These findings emphasize the need for developmental-stage-specific items on measures of DD given that so many participants identified developmentally specific aspects of DD that are not on the PAID. For example, although the PAID has items about worries for the future, the PAID-EA items specify what this worry feels like for emerging adults who are beginning to concretely plan their future, including beginning their career and starting a family. Studies from Europe have noted that T1D can impact career choice and thus future earning potential^{37,38}; this study emphasizes that worries about these decisions can be particularly heavy during this life stage. Additionally, many participants reported substantial worries about having children in the future, not just those who identify as women, as others have reported.⁷ The PAID, or other measures of DD, may not capture the complexity of the experience of the emotional burden of T1DM during this life stage and may potentially underestimate DD because it is not sufficiently sensitive to these stage-specific emotions and worries.

Notably, the code identified by the most participants as being particularly meaningful was related to the cost of diabetes. In fact, the PAID-EA is the only measure of DD that includes an item addressing the financial stress of diabetes. As seen in prior psychometric validation work,^{18,20} this item also had the highest mean score, indicating that most participants endorsed this item as an area of burden. Recent awareness of cost concerns suggests that this worry is particularly meaningful for emerging adults living in the United States given the complexities of health care cost and access in this country.³⁹ Many participants identified multiple dimensions of worry about cost from 1 very simple question and connected it to worries about insurance although that topic was not specifically addressed in the survey. The findings suggest that the worry about the cost of diabetes is rather complicated and includes disparate aspects, such as access to care, finding employment, and fear about turning 26 and aging out of parental insurance coverage. Although much of this worry may be specific to living in the United States, this concern appears to be considerable and necessitates further investigation.

This report highlights the benefits of including open-ended questions about the survey content, which not only allowed for evaluation of content validity of the newly developed PAID-EA measure but also provided a window into the experience of DD among emerging adults. The absence of an interviewer in the collection of these qualitative data allowed for unfiltered and unbiased responses. These answers were powerful and provided insight into the challenges of this disease for emerging adults.

Limitations

Despite attention to rigor, this study did have some limitations. This study used a cross-sectional convenience sample of emerging adults living in the United States recruited through social media and electronic communication due to the COVID-19 pandemic, which

may limit generalizability of some of the findings. In fact, this sampling technique captured a sample of mostly White women with higher socioeconomic status, with a majority using diabetes technologies and with close to target glycemic control. These sampling issues may impact the measurement of the emotional burden of living with T1D. Further research in more diverse samples is needed.

Conclusions and Future Directions

In this cross-sectional study to further validate the PAID-EA, the responses to open-ended questions provided a poignant picture of the challenges of life with T1D for this population. These findings support the PAID-EA as a promising, reliable, valid, and developmentally embedded measure of DD in emerging adults. Although the PAID-EA must be subjected to further psychometric testing, it has the potential to advance the science of measurement of the emotional burden of T1DM. Importantly, this qualitative analysis revealed that fear of the future, concerns about the cost of diabetes, acute worries about life with diabetes, and challenges finding adequate diabetes support were the most important components of DD for emerging adults with T1D. These developmental-stage-specific challenges must be measured and recognized as important to better support emerging adults living with T1D.

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Table 1.Participant Characteristics (N = 254)^a

Age (y)	24 (18–30)
Age at diagnosis (y)	11 (1–26)
Self-reported A1C (%)	7.1 ± 1.2 (4.9–11.4)
Gender: Women	201 (79%)
Men	50 (20%)
Identify another way	3 (1%)
Race (% White)	229 (90%)
Identify as another race (can include White)	25 (10%)
Hispanic ethnicity	26 (10%)
Currently a full-time student	109 (43%)
Part-time student	18 (7.1%)
Have own health insurance	119 (47%)
On parents' health insurance	131 (52%)
Uninsured	4 (1.6%)
Used insulin pump in last month	198 (78%)
Used continuous glucose monitor in last month	228 (90%)
COVID-19 impact on life (% moderate or severe)	170 (67%)
COVID-19 impact on mood (% worse than before)	177 (70%)

^aContinuous data are median (range) for age, age at diagnosis; mean ± SD (range) for A1C. Categorical data are n (%).

Table 2.

Items on the PAID-EA, PAID, and CES-D Organized by Corresponding Theme for the Most Meaningful Emotions and Worries Identified by Participants

Theme 1: Fear of the future

PAID-EA items:

- Item 8: I worry about having kids in the future because of my diabetes.
 Item 10: I worry that diabetes will get in the way of what I want to do with my life.
 Item 19: I worry about diabetes complications.

PAID items:

- Item 3: Feeling scared when you think about Living with diabetes.
 Item 12: Worrying about the future and the possibility of serious complications.

CES-D items:

- Item 8: felt hopeful about the future. (reverse-coded item)
 Item 10: I felt fearful.

Subtheme: Worry about the cost of diabetes

PAID-EA items:

- Item 21: I worry about the cost of diabetes.

PAID items:

None

CES-D items:

None

Theme 2: Acute worries about living with diabetes

PAID-EA items:

- Item 1: I feel that diabetes is taking up too much of my mental energy every day.
 Item 11: I feel that I must be perfect in my diabetes management.
 Item 14: I feel like a failure when I have a high A1C.
 Item 17: I don't want to know my blood sugar when it is high.
 Item 22: I worry about having a low blood sugar.
 Item 23: I am too tired of having diabetes to take care of it.
 Item 25: I feel like I am trying my hardest to take care of diabetes, but it never works.

PAID items:

- Item 8: Feeling overwhelmed by your diabetes.
 Item 9: Worrying about low blood glucose reactions.
 Item 13: Feelings of guilt or anxiety when you get off track with your diabetes management.
 Item 16: Feeling that diabetes is taking up too much of your mental and physical energy every day.
 Item 20: Feeling "burned out" by the constant effort needed to manage diabetes.

CES-D items:

None

Theme 3: Challenges with finding support

PAID-EA items:

- Item 2: I feel annoyed when people say something ignorant about having diabetes.
 Item 3: I am tired of having to explain diabetes to others.

Item 5: I feel judged by others because I have diabetes.

Item 6: I worry about being able to socialize because of how alcohol affects my blood sugar.

Item 7: I worry that a new romantic partner will see my diabetes devices.

Item 12: I feel alone with diabetes.

Item 13: I avoid doing diabetes management tasks when other people are around.

Item 15: I feel overwhelmed about having to do diabetes all by myself.

Item 16: I worry about living alone because I have diabetes.

Item 24: I feel like I cannot take as many risks as my friends.

PAID items:

Item 4: Uncomfortable social situations related to your diabetes care (eg, people telling you what to eat)

Item 17: Feeling alone with your diabetes.

Item 18: Feeling that your friends and family are not supportive of your diabetes management efforts.

CES-D items:

Item 3: I felt that I could not shake off the blues even with the help from my family or friends.

Item 4: I felt I was just as good as other people. (reverse-coded item)

Item 14: I felt lonely.

Item 15: People were unfriendly.

Item 19: I felt that people dislike me.

Items that did not correspond to a specific theme

PAID-EA items:

Item 4: have other things in my life that keep me from managing my diabetes.

Item 9: I worry that my blood sugar will go high or low during sex.

Item 18: I feel frustrated about interruptions from diabetes (during sleep, work, school).

Item 20: I don't know how to make diabetes a priority when I have a lot of changes in my life.

PAID items:

Item 1: Not having clear and concrete goals for your diabetes care.

Item 2: Feeling discouraged with your diabetes treatment plan.

Item 5: Feelings of deprivation regarding food and meals.

Item 6: Feeling depressed when you think about living with diabetes.

Item 7: Not knowing if your mood or feelings are related to your diabetes.

Item 10: Feeling angry when you think about living with diabetes.

Item 11: Feeling constantly concerned about food and eating.

Item 14: Not "accepting" your diabetes.

Item 15: Feeling unsatisfied with your diabetes physician.

Item 19: Coping with complications of diabetes.

CES-D items:

Item 1: was bothered by things that usually don't bother me.

Item 2: I did not feel like eating; my appetite was poor.

Item 5: I had trouble keeping my mind on what I was doing.

Item 6: I felt depressed.

Item 7: I felt everything I did was an effort.

Item 9: I thought my life had been a failure.

Item 11: My sleep was restless.

Item 12: I was happy. (reverse-coded item)

Item 13: I talked less than usual.

Item 16: I enjoyed life. (reverse-coded item)

Item 17: I had crying spells.

Item 18: I felt sad.

Item 20: I could not get "going."

Abbreviations: CES-D, Center for Epidemiologic Studies Depression Scale; PAID, Problem Areas in Diabetes; PAID-EA, Problem Areas in Diabetes-Emerging Adult.

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