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BRIEF REPORT

“Fear That One Day I May Not Be Able to Afford Insulin”: The Emotional Burden of Diabetes Costs During Emerging Adulthood

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Abstract

Emerging adults (EAs) with type 1 diabetes (T1D) often experience challenges in diabetes management, in particular transitioning to financial independence. EAs 18–30 years of age with T1D completed online surveys about diabetes distress and an open-ended query about the most important worry among survey questions. Most of the 287 respondents (89.5%) endorsed “Agree” or “Somewhat agree” to the statement “I worry about the cost of diabetes.” Responses did not differ by gender, age, diabetes duration, race/ethnicity, diabetes technology use, student status, income, or insurance status. However, a greater proportion of those not endorsing cost as a substantial burden achieved A1c <7% (92.9%) versus those who were neutral (46.2%) or who endorsed cost as a burden (50.6%) ($P=0.004$). Furthermore, in open-ended responses, cost was the most frequently noted worry. Diabetes costs are a major concern for EAs, likely contributing to diabetes distress during this developmental stage, and clinicians should consider discussing diabetes costs with this population.

Keywords: Type 1 diabetes, Emerging adults, Diabetes distress, Diabetes costs.

Introduction

EMERGING ADULTS (EAs) LIVING WITH type 1 diabetes (T1D) have unique challenges in diabetes management specific to their developmental stage.^{1,2} Arnett³ defined emerging adulthood as ages 18–30, when young people living in modern industrialized societies experience extended identity exploration. This period is marked by frequent dislocation, new academic or work settings, and changing peer and family support. Diabetes management may become more challenging when an individual experiences multiple transitions and disruptions in support structures. This instability likely contributes to increased diabetes distress,⁴ more fre-

quent diabetic ketoacidosis,⁵ and higher A1cs during this developmental stage.⁶

Many EAs are working toward financial independence and may be learning about diabetes costs for the first time.⁷ The consumer cost of T1D has risen dramatically over the last few decades.^{8–10} While the exponential rise of the cost of insulin over the last 20 years has received significant publicity and political attention,⁹ diabetes costs come from a variety of sources, including insulin pump and continuous glucose monitoring (CGM) supplies, glucagon, blood glucose and ketone test strips, co-pays for medical appointments, and the cost of lost productivity due to the burden of diabetes management.^{11,12} Gross per-person spending on health care for

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people with T1D increased from \$12,467 to \$18,494 per year between 2012 and 2016.¹³ This 48% increase was largely driven by a 99% increase in the cost of insulin.¹³ These increasing costs have been passed along to the consumer; out-of-pocket expenditures for T1D increased by 54% between 2005 and 2017.⁸

Despite the continually rising costs of T1D, there has been little exploration about the weight of this worry on EAs specifically. Therefore, a new measure of diabetes distress, entitled the Problem Areas in Diabetes-Emerging Adult (PAID-EA) survey, was developed, which includes one item on the worry about the costs of diabetes. This report describes the emotional burden of cost by evaluating both salient participant factors associated with worry about the costs of diabetes and a qualitative analysis of responses to an open-ended query.

Methods

A cross-sectional online survey was administered using recruitment approaches described previously using Qualtrics software (Qualtrics, Provo, UT).¹⁴ Entry criteria included participants 18–30 years old with T1D and English fluency. All phases of this project were approved by the Institutional Review Board and participants provided informed consent before any study procedure commenced.

The online survey included demographic and clinical questions, as well as the original PAID¹⁵ and the Center for Epidemiologic Studies Depression Scale,¹⁶ which were both used for psychometric validation analyses.¹⁴ The 25-item PAID-EA, with 5-point Likert-type response options scored as 0–4, reflects the emotional burden of living with T1D specific to the developmental stage of emerging adulthood.^{14,17} Higher scores indicate more diabetes distress. Responses to the PAID-EA item “I worry about the cost of diabetes” were analyzed using Fisher’s exact test (SAS 9.4, Cary, NC) to assess participant factors associated with cost-related diabetes distress.

The survey concluded with open-ended queries, including, “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.” Responses to the open-ended questions were analyzed using directed qualitative content analysis.¹⁸ The responses were read by two authors (K.W. and R.J.V.) and coded independently. Then codes were compared, with L.M.B.L. available to adjudicate disagreements. The codes were placed into categories and sub-categories and then organized into themes; the results of the complete analysis are reported elsewhere.¹⁹ Only responses to the question regarding the most important concern are included in this report, focusing on responses highlighting the costs of diabetes.

Results

Quantitative analysis

The survey was completed by 287 participants, of whom 78% were female, 81.9% identified as non-Hispanic white, and the mean age was 24 years (range 18–30). The participants had a mean self-reported A1c of 7.1% (range 4.9–11.4)

and most of them used diabetes technology: 89.9% reported CGM use and 78.0% insulin pump use in the last month.

In response to the item “I worry about the cost of diabetes,” 89.5% of participants responded “Agree” or “Somewhat agree,” which was the highest percentage of item endorsement in the PAID-EA (range among other items: 30.7%–88.9%). As reported in Table 1, responses did not differ by many sociodemographic and diabetes-related factors, specifically gender ($P=0.829$), age ($P=0.684$), diabetes duration ($P=0.643$), race/ethnicity ($P=0.862$), student status ($P=0.432$), annual income ($P=0.572$), insurance status ($P=0.457$), CGM use ($P=0.319$), or insulin pump use ($P=0.065$). Among those not endorsing cost concerns as a burden, a significantly larger proportion achieved the A1c glycemic target of <7% (92.9%) versus those who were neutral (46.2%) or who endorsed costs as a burden (50.6%) ($P=0.004$).

Open-ended responses

Two hundred fifty-one of 287 participants (87%) also responded to the open-ended question. In the qualitative responses regarding the most important or significant diabetes-related concern, cost was cited more frequently than any other concern. Worry about insurance coverage was also meaningful and likely relates to concerns about health care costs for young people living in the United States. Some participants went as far as expressing that losing insurance would be tantamount to losing everything in their lives:

“Loss of insurance and not being able to afford it and losing everything” (Female, age 26)

Many people also expressed their feelings about diabetes costs as not just a concern, but a fear:

“Fear. Fear that one day I may not be able to afford insulin.” (Female, age 25)

Some participants specifically discussed the frustrations they felt when dealing with issues of costs, especially when their peers did not have such burdens:

“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...it’s all just very overwhelming.” (Female, age 19)

Insurance coverage is particularly salient in the EA age group in the United States as young adults lose access to their parents’ insurance at age 26. To avoid gaps in coverage, the EA must acquire independent coverage by 26, either through their employer or through public mechanisms, both of which may be costly and/or difficult to navigate. Several respondents specifically called out anxieties about loss of insurance access at this age:

“I am also worried about when I turn 26, how I am going to pay for my diabetes care & supplies. It seems that the cost increases more & more each time. It is frightening & somewhat depressing to think of a future.” (Female, age 18)

“I worry about turning 26 and being taken off my mom’s insurance. I have so much anxiety about it. And I know that there are resources out there to help me, but I just can’t get myself to start looking and applying for medical insurance. I think I’m in denial?” (Female, age 25)

TABLE 1. RESPONSES TO PROBLEM AREAS IN DIABETES-EMERGING ADULT ITEM: "I WORRY ABOUT THE COST OF DIABETES" BY DEMOGRAPHIC AND CLINICAL CHARACTERISTICS^a

	Overall (n=287)	Disagree or somewhat disagree (n=17)	Neutral (n=13)	Agree or somewhat agree (n=257)	P ^b
Gender, n (%)					0.829
Female	224 (78.1)	15 (88.2)	10 (76.9)	199 (77.4)	
Male	60 (20.9)	2 (11.8)	3 (23.1)	55 (21.4)	
Identify another way	3 (1.1)	0 (0)	0 (0)	3 (1.2)	
Age, n (%)					0.684
<25 years	143 (54.0)	7 (46.7)	6 (46.2)	130 (54.9)	
≥25 years	122 (46.0)	8 (53.3)	7 (53.9)	107 (45.2)	
Diabetes duration, n (%)					0.643
<12 years	113 (43.6)	7 (50.0)	7 (53.9)	99 (42.7)	
≥12 years	146 (56.4)	7 (50.0)	6 (46.2)	133 (57.3)	
Race/Ethnicity, ^c n (%)					0.862
Non-Hispanic White	235 (81.9)	14 (82.4)	10 (76.9)	211 (82.1)	
Identify another way	52 (18.1)	3 (17.7)	3 (23.1)	46 (17.9)	
Student status, n (%)					0.432
Full time	124 (43.4)	5 (29.4)	6 (46.2)	113 (44.1)	
Part time	21 (7.3)	1 (5.9)	2 (15.4)	18 (7.0)	
Not a student	141 (49.3)	11 (64.7)	5 (38.5)	125 (48.8)	
Annual income, n (%)					0.572
<\$75,000	137 (51.1)	7 (58.3)	4 (36.4)	126 (51.4)	
≥\$75,000	131 (48.9)	5 (41.7)	7 (63.6)	119 (48.6)	
Insurance status, n (%)					0.457
Own insurance	134 (46.7)	9 (52.9)	6 (46.2)	119 (46.3)	
Parents' insurance	149 (51.9)	7 (41.2)	7 (53.9)	135 (52.5)	
Uninsured	4 (1.4)	1 (5.9)	0 (0)	3 (1.2)	
CGM use, n (%)					0.319
Yes	257 (89.9)	17 (100)	11 (84.6)	229 (89.5)	
No	29 (10.1)	0 (0)	2 (15.4)	27 (10.6)	
Insulin pump use, n (%)					0.065
Yes	223 (78.0)	15 (88.2)	13 (100)	195 (76.2)	
No	63 (22.0)	2 (11.8)	0 (0)	61 (23.8)	
A1c, n (%)					0.004
A1c <7%	147 (52.5)	13 (92.9)	6 (46.2)	128 (50.6)	
A1c ≥7%	133 (47.5)	1 (7.1)	7 (53.9)	125 (49.4)	

^aSome participants did not answer all demographic and clinical questions. Data noted to be missing for the following characteristics: age ($n=22$), diabetes duration ($n=28$), student status ($n=1$), income ($n=19$), CGM use ($n=1$), insulin pump use ($n=1$), and A1c ($n=7$).

^b p values from Fisher's exact tests. Significant results ($P<0.05$) are bolded.

^cParticipants were able to select multiple racial identifiers (American Indian/Alaskan Native, Asian, Black/African American, Native Hawaiian or other Pacific Islander, White) and completed a separate question for Hispanic ethnicity.

CGM, continuous glucose monitoring.

Discussion

Of the many unique challenges EAs with T1D encounter, diabetes costs are particularly notable. In our sample of EAs, the quantitative analysis did not identify any socio-demographic factor, such as age, gender, or student status, which was protective against the distress related to diabetes costs. While there was a trend toward less technology use among those not experiencing cost-related distress, this was not statistically significant. Those who did not endorse worry about diabetes costs were more likely to achieve glycemic targets.

No causative conclusion can be drawn from this cross-sectional data, but it is possible that those who have fewer cost concerns have less cost-related diabetes distress, which may lead to better glycemic outcomes. Alternately, those

with greater cost concerns may not be able to afford advanced technologies, which could make achieving lower A1cs more challenging. In our sample, there was a trend toward lower CGM and pump use among those who endorsed cost-related distress, suggesting a need for further research in a more diverse sample.

Another possibility is that those who cannot afford their diabetes supplies may be driven to ration supplies or insulin, contributing to higher A1cs. One in four people with insulin-dependent diabetes in the United States use less insulin than prescribed due to the cost of the medication and those who did ration insulin were more likely to have higher A1cs.²⁰ In addition, a recent study showed that nearly 30% of people with T1D in the United States had rationed insulin and nearly 40% performed limited blood glucose testing due to the cost of supplies.¹¹ Given this known association with insulin

rationing and higher A1cs, it is not surprising that those not meeting A1c targets reported more concerns about diabetes costs.

The qualitative analysis of the open-ended question highlights the impact that diabetes costs have on many different dimensions of young peoples' lives. Participants described cost concerns as all-consuming and a source of fear. They also reported feelings of isolation, and diabetes cost concerns intensified their feelings of limitation and unfairness. Fear of insurance loss likely deepened distress experienced by EAs, especially for those navigating transition to financial independence. The participant quotes demonstrated the weight of this concern on their psychological state. As the PAID-EA is the first measure of diabetes distress to include an item about cost, the extent to which diabetes costs impact EAs, and possibly all people with diabetes, may have been underestimated in the past.

The ability to afford diabetes supplies is a topic that is largely under-addressed by clinicians in medical visits, especially during the transition from pediatric to adult diabetes care. While templates and checklists for successful transitions do exist, budgeting for medical costs and the emotional burden of these concerns are not included.^{21,22} Recently, a randomized pilot trial of the T1D Financial Toolkit for EAs, consisting of 10 short videos focused on financial and health insurance education, was found to be feasible and acceptable. The videos cover topics such as budgeting for diabetes expenses, enrolling in an insurance plan, and obtaining backup medications and supplies.²³ More such resources are needed for patients, and clinicians may benefit from education about the challenges of diabetes costs to better support their patients.

One study limitation is the potentially nonrepresentative sample, as recruitment occurred online during the COVID-19 pandemic. This led to a sample of mostly non-Hispanic white women with higher-than-average income using diabetes technology and meeting glycemic targets; thus, results may not be generalizable. As diabetes technology is costly, this sample may have higher diabetes costs than average, which could cause an overestimation of cost-related distress. Conversely, this seemingly wealthier sample may have more financial resources, leading to an underestimation of cost-related distress. More research is needed to confirm these findings in a more diverse sample. In addition, this was a post-hoc exploratory analysis for which the study was not specifically powered.

Conclusion

The unchecked rise in diabetes costs over the last few decades, fueled largely by the increase in insulin prices, has had significant impacts on both physical and psychological health of people with T1D. Worry about the costs of diabetes appears to be massive and contributes meaningfully to the emotional burden of T1D for EAs, as demonstrated in this mixed-methods analysis. It may be timely for clinicians to begin proactive discussions about the costs of diabetes with their EA patients, especially those with A1cs above target, and help them find resources that can help.

However, teaching patients financial planning will only go so far if the costs continue to rise at such untenable rates. Advocacy and activism are likely necessary to reduce the

overall costs of diabetes. Many diabetes-related professional societies, such as the Endocrine Society and American Diabetes Association, have advocacy sections to help clinicians who are interested in becoming more involved. In addition, the T1International #insulin4all campaign has local chapters in most states and can help support people with limited advocacy experience. The entire diabetes community can use their voices for such change.

Authors' Contributions

R.J.V.: formal analysis (lead); writing—original draft (lead); and writing—review and editing (equal). K.W.: conceptualization (lead); methodology (lead); investigation (lead); data curation (lead); and writing—review and editing (equal). L.M.B.L.: supervision (lead) and writing—review and editing (equal).

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