







Learning Objectives

1. Describe the problem and prevalence of cost-related barriers in emerging adults with T1D
2. Discuss the self-management experiences of emerging adults with T1D who encounter cost-related barriers
3. Provide practical pearls for educating and supporting emerging adults who experience cost-related barriers

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Disclosure to Participants

- Notice of Requirements For Successful Completion
 - Please refer to learning goals and objectives
 - Learners must attend the full activity and complete the evaluation in order to claim continuing education credit/hours
- Conflict of Interest (COI) and Financial Relationship Disclosures:
 - Presenter: Julia Blanchette, PhD(c), RN, CDE- clinical consultant/financial- Tandem Diabetes, clinical consultant/financial- Dexcom
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Introduction: Emerging Adulthood

- Developmental period between childhood and adulthood¹
- Ages 18-25 vs 18-30^{1,8}
 - Phase 1: Ages 18-24^{1,8}
 - Phase 2: Ages 25-30^{1,8}
- Period of identity exploration, emotional instability, hope, risk-taking, financial insecurity, self-focus¹
- **Developmental milestones of financial, living, and self-management independence**^{1,2,7-9}
- Transition from pediatric to adult health care^{2,8}
- Begin to transition away from parental support¹⁻²
- Experience frequent changes/lapses in health insurance coverage, popularity of high-deductible plans⁹
- Lower starting salary's⁹

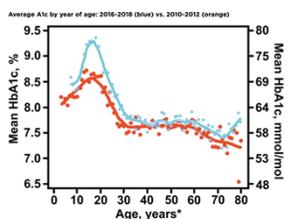


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Background

Self-Management

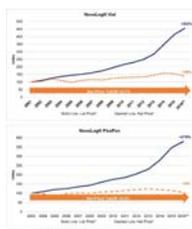
- ~85% of emerging adults do not meet optimal self-management goals⁴
- Increases in the incidence of DKA and long-term diabetes—related complications¹
- Lapses in diabetes care



Average HbA1c by age from the T1D Exchange (Foster et al., 2019)

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Background



Reported changes in Novolog list and net prices since 2003 (Cefalu et al., 2018)

Cost-Related Barriers

- Cost of insulin increased as much as 350% in the past 15 years⁶⁻⁷
- Diabetes costs can exceed \$1,000/month⁸
- Cost-related financial stress leads to insulin rationing, suboptimal self-management outcomes, and long-term complications⁵

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Study Significance

Address Research Gaps

- T1D self-management barriers during emerging adulthood
 - Not fully understood
 - Influenced by barriers such as stress
- Cost-related barriers
 - Remain unexplored in emerging adults with T1D
 - Relevant and potentially detrimental effect on self-management

Self-Management

- Improve current self-management education and diabetes care provided to emerging adults with T1D
- Awareness of unique and critical issues relevant to self-management in emerging adults with T1D

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Study Aims

- This study aims to describe the prevalence of cost-related barriers to self-management experienced by emerging adults, ages 18-25, with T1D by administration of developmentally tailored, open-ended survey questions.

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METHODS

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Study Design

- Descriptive
- Cross-sectional
- Secondary analysis (N=267)
 - Parent study (N=500)
 - Financial stress factors, psychological symptoms and self-management outcomes
- Quantitative content analysis

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Sample

Inclusion Criteria	Exclusion Criteria
Diagnosis of T1D	Inability to answer questions due to cognitive status
Current age 18-25	Inability to read or understand English
Age of T1D dx \leq 18 years	Dx of other form of diabetes
Disease duration of \geq one year	Pregnancy
Valid email address	

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Sample

T1D Exchange Clinic Registry

- JAEB Center for Health Research
- Largest T1D clinic-based registry in US
- Over 9,000 emerging adults
- Diverse group, wide range of educational levels, socioeconomic statuses, and regions in the United States (77 clinical sites in 35 states)
- Predominately white (non-Hispanic) (77.51%)
- Annual family income of $>$ \$100,000 (25.27%)

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Recruitment

- Convenience sampling
- Power analysis for parent study
 - N=146
 - G*Power
 - Significance level of .05, power of .80, medium effect size of .15 for multiple regression analysis

The T1D Exchange

- Sent recruitment email to those who met inclusion criteria
- Inclusion and exclusion criteria in email
- Description of the research study
- Contact info for Case Western research team
- Link to the REDCap platform for informed consent and data collection

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Data Collection

REDCap

- Accessed via participants' personal internet devices
- Cloud-based, secure server
- Informed consent
- Survey administration
- Invitation to answer additional open-ended questions regarding experiences with the cost of diabetes at survey completion

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Open-Ended Questions

Emerging Adults

- Developmentally prone to omitting or providing conservative responses to open-ended, personal questions

Survey Questions

- Normalized cost-saving behaviors to encourage open, honest and comfortable responses

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Open-Ended Questions

- (1) In order to save money, some people have rationed insulin and diabetes supplies. Describe your experiences with this.
- (2) Some people report using expired insulin or supplies. Tell me about your experiences with this.
- (3) Describe your experiences with refilling prescriptions for insulin or diabetes supplies. Specifically, what difficulties have you experienced refilling prescriptions?
- (4) Some people report reusing needles and diabetes supplies. What experiences have you had with this?

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Analysis

- Coded dichotomously
 - Did not ask yes/no question, was open-ended
 - Almost all responses were able to be categorized and coded into...
 - Provided examples of experiences/Yes (1)
 - Did not provide examples of experiences/No (0)
- Descriptive statistics
 - Qualitative: Content frequencies
 - Demographics: Frequencies

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RESULTS

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Sample Characteristics (N=267)

Characteristics	
Age in years, mean (SD)	22.16 (1.84)
Gender, n (%)	
Female	167 (63.5)
Male	96 (36.5)
Education, n (%)	
High School diploma	31 (11.7)
Some college/associate's degree	137 (51.7)
Bachelor's degree or higher	97 (36.6)
Annual Income, n (%)	
<\$25,000	179 (66.8)
\$25,001-\$49,999	56 (20.9)
\$50,000-\$74,999	21 (7.8)
>\$75,000	12 (4.5)

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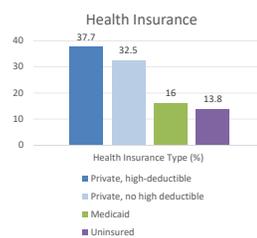
Sample Characteristics (N=267)

Characteristics	
Living situation, n (%)	
Parents/family	97 (48.7)
Partner/spouse	44 (22.1)
Roommates	38 (19.1)
Independently	20 (10.1)
Employment, n (%)	
Full-time employed	88 (32.8)
Part-time employed, full time student	83 (31.0)
Student	42 (15.7)
Unemployed	29 (10.8)
Part-time employed	26 (9.7)
Race, n (%)	
White, non-Hispanic	220 (87.3)
Hispanic/Latino	21 (8.3)
Black/African American	8 (3.2)

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Sample Characteristics

Health Insurance Characteristics	
Insurance Type n (%)	
Private	188 (70.1)
Medicaid	43 (16.0)
Uninsured	37 (13.8)



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Diabetes/Health Characteristics (N=267)

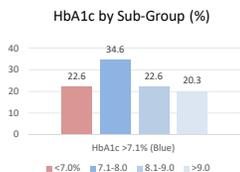
Diabetes Characteristics	
Disease Duration in years, mean (SD)	13.23 (4.52)
Provider Type n (%)	
Adult	178 (67.7)
Pediatric	69 (26.2)
No Provider	16 (6.1)

Technology Usage	
Insulin Pump Usage n (%)	
Yes	184 (68.7)
No	84 (31.3)
CGM Usage n (%)	
Yes	152 (56.7)
No	116 (43.2)

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Diabetes-Related Characteristics (N=267)

HbA1c Characteristics	
HbA1c, mean (SD)	8.13 (1.67)
Range n (%)	
≤7.0%	60 (22.6)
≥7.1%	206 (77.4)



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Qualitative Content Analysis

Provided examples of experiences/yes	n	%
Q1. Difficulty refilling insulin or supplies	192	71.9
Q2. Reusing needles and other supplies	183	70.9
Q3. Using expired insulin or supplies	130	53.1
Q4. Rationing insulin or supplies	105	43.4

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Q1. Describe your experiences with refilling prescriptions for insulin or diabetes supplies. Specifically, what difficulties have you experienced refilling prescriptions?

Provided examples of experiences/Yes (n=192, 71.9%)

Examples

"Sometimes the insurance company makes you change insulin brands... they only let you have so much a month and prices are outrageous, causing me to have to ration out my insulin."

"I have had difficulty with filling prescriptions and keeping the cost affordable. They often don't want to accept the manufacturer's coupon I have. It is always a battle."

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Q1. Describe your experiences with refilling prescriptions for insulin or diabetes supplies. Specifically, what difficulties have you experienced refilling prescriptions?

Did not provide examples of experiences/No (n=75, 28.1%)

Examples

"My parents have done my prescriptions up to this point, I'm worried I don't know what to do."

"None. My mother does it."

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Q2. Some people report reusing needles and diabetes supplies. What experiences have you had with this?

Provided examples of experiences/Yes (n=183, 70.9%)

Examples

"I reuse needles all the time. Feels like a waste to not reuse them."

"I have used insulin pump sites longer than intended because insurance/financial issues."

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Q2. Some people report reusing needles and diabetes supplies. What experiences have you had with this?

Did not provide examples of experiences/No (n=75, 29.1%)

Examples

"I do not reuse needles, I just won't test if I don't have money to buy new ones."

"I have not reused needles or diabetes supplies, the health risks associated with that are too great to chance."

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Q3. Some people report using expired insulin or supplies. Tell me about your experiences with this.

Provided examples of experiences/Yes (n=130, 53.1%)

Examples

"Desperate times call for desperate measures. If that's all you have, it's a better option than dying."

"I have used expired insulin from the past, especially if lapses between insurance coverage or employment."

"If I have the insulin, I will use it no matter if it's expired or not. It's just too valuable to me."

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Q3. Some people report using expired insulin or supplies. Tell me about your experiences with this.

Did not provide examples of experiences/No (n=115, 46.9%)

Examples

"No because my mom usually stocks up in case there is a shortage or if it is overpriced."

"No. I don't have supplies long enough for them to expire."

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Q4. In order to save money, some people have rationed insulin and diabetes supplies. Describe your experiences with this.

Provided examples of experiences/Yes (n=105, 43.3%)

Examples

"I ration carbs the last week of the month to conserve insulin."

"Sometimes I will run my blood sugar a little high to make the insulin last longer."

"I was definitely rationing insulin when I was paying out of pocket last year. Was a scary experience."

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Q4. In order to save money, some people have rationed insulin and diabetes supplies. Describe your experiences with this.

Did not provide examples of experiences/No (n=137, 56.6%)

Examples

"Luckily, I have been able to do the opposite and stockpile insulin and supplies when they are affordable."

"Thankfully I haven't had to do this. I worry that when I no longer have my mom's insurance I will have to."

I am fortunate that I have not had to do this, but it is something I worry about. If I did not live with my parents I don't think I could afford the cost of an apartment and my medical supplies.

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**DISCUSSION:
CLINICAL PRACTICE PEARLS**

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Clinical Implications

- It is vital for diabetes educators to be aware of barriers when setting self-management goals with emerging adults with T1D
- **Open the discussion, assess for cost-related barriers**
- Prepare for financial emergencies
 - Provide resources
 - Back-up plan
 - Strategies to navigate

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Practice Pearls

Financial Assistance Resources (for PWD and providers)

- AADE Insulin Cost Savings Resource Guide
 - Break down by medication type
 - Copay cards, other financial resources
 - Tips for maximizing savings
- AADE Accessibility and Affordability Resources
 - Insulin affordability resource
 - Affordable insulin project
 - AACE prescription savings directory
 - T1D Health Insurance Guide (JDRF)
 - Patient assistance resources from Eli Lilly
 - AADE Tip Sheet: Non-Medical Switching: Ways to Help Your Patients Obtain the Medications That Were Prescribed for Them

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Resources

AADE Cost-Saving Resource Guide:

<https://www.diabeteseducator.org/docs/default-source/practice/educator-tools/insulin-cost-saving-resources-3-4-19.pdf>

AADE Accessibility and Affordability Resources

<https://www.diabeteseducator.org/practice/educator-tools/app-resources/affordability-resources>

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CONCLUSIONS

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Strengths & Limitations

Strengths	Limitations
Very large N for qualitative	Cross-sectional
Generalizable across US	Bias- self-selected group, motivated due to study topic
Relevant, novel topic	Beginning stages of analysis (not a full thematic analysis)

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Future Research

- Further investigate cost-related self-management barriers in this population and other diabetes populations
- Parent study
 - Perform thematic analysis of the qualitative data
 - What are common themes in refill difficulties, rationing reusing and expired supplies?
 - Mixed methods with qualitative responses
 - Correlational, descriptive analysis of financial stress factors, psychological symptoms and self-management outcomes

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Conclusions

- Majority of emerging adults with T1D in this study reported cost-related barriers and altered self-management decisions and behaviors
- Recommendations for Diabetes Educators
 - Advocate for policies that support accessible and affordable diabetes care
 - Increase awareness of cost-related barriers in the clinical setting
 - Deliver developmentally tailored diabetes education and care to emerging adults

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Questions?

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