The Prevalence of Cost-Related Self-Management Barriers in Emerging Adults with T1D

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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

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
  - Tandem Diabetes, clinical consultant
  - Dexcom

- Non-Endorsement of Products
  - Accredited status does not imply endorsement by AADE, ANCC, ACPE or CDR of any commercial products displayed in conjunction with this educational activity

- Off-Label Use:
  - Participants will be notified by speakers to any product used for a purpose other than for which it was approved by the Food and Drug Administration

Introduction: Emerging Adulthood

- Developmental period between childhood and adulthood
- Ages 18-25 vs 18-30
  - Phase 1: Ages 18-24
  - Phase 2: Ages 25-30
- Period of identity exploration, emotional instability, hope, risk-taking, financial insecurity, self-focus
- Developmental milestones of financial, living, and self-management independence
- Transition from pediatric to adult health care
- Begin to transition away from parental support
- Experience frequent changes/talks in health insurance coverage, popularity of high-deductible plans
- Lower starting salary
**Background**

**Self-Management**
- ~85% of emerging adults do not meet optimal self-management goals.
- Increases in the incidence of DKA and long-term diabetes-related complications.
- Lapses in diabetes care.

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

**Cost-Related Barriers**
- Cost of insulin increased as much as 350% in the past 15 years.
- Diabetes costs can exceed $1,000/month.
- Cost-related financial stress leads to insulin rationing, suboptimal self-management outcomes, and long-term complications.

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

**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
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.

METHODS

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
Sample

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis of T1D</td>
<td>Inability to answer questions due to cognitive status</td>
</tr>
<tr>
<td>Current age 18-25</td>
<td>Inability to read or understand English</td>
</tr>
<tr>
<td>Age of T1D dx ≤ 18 years</td>
<td>Dx of other form of diabetes</td>
</tr>
<tr>
<td>Disease duration of ≥ one year</td>
<td>Pregnancy</td>
</tr>
<tr>
<td>Valid email address</td>
<td></td>
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</tbody>
</table>

**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 cites in 35 states)
  - Predominately white (non-Hispanic) (77.51%)
  - Annual family income of >$100,000 (25.27%)

**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
## 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

## 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

## 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?
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

RESULTS

Sample Characteristics (N=267)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency (n)</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (in years, mean (SD))</td>
<td>22.16(1.84)</td>
<td></td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>167 (63.5)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>96 (36.5)</td>
<td></td>
</tr>
<tr>
<td>Education, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school diploma</td>
<td>31 (11.7)</td>
<td></td>
</tr>
<tr>
<td>Some college/associate’s degree</td>
<td>137 (51.7)</td>
<td></td>
</tr>
<tr>
<td>Bachelor’s degree or higher</td>
<td>97 (36.6)</td>
<td></td>
</tr>
<tr>
<td>Annual Income, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$25,000</td>
<td>179 (66.8)</td>
<td></td>
</tr>
<tr>
<td>$25,001-$49,999</td>
<td>56 (20.9)</td>
<td></td>
</tr>
<tr>
<td>$50,000-$74,999</td>
<td>21 (7.8)</td>
<td></td>
</tr>
<tr>
<td>&gt;$75,000</td>
<td>12 (4.5)</td>
<td></td>
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</table>
Sample Characteristics (N=267)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living situation</td>
<td></td>
</tr>
<tr>
<td>Parents/Family</td>
<td>97 (48.7)</td>
</tr>
<tr>
<td>Partner/Spouse</td>
<td>44 (22.1)</td>
</tr>
<tr>
<td>Roommates</td>
<td>38 (19.1)</td>
</tr>
<tr>
<td>Independently</td>
<td>30 (18.1)</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
</tr>
<tr>
<td>Full-time employed</td>
<td>88 (32.8)</td>
</tr>
<tr>
<td>Part-time employed, full time student</td>
<td>83 (31.0)</td>
</tr>
<tr>
<td>Student</td>
<td>43 (16.3)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>26 (9.7)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>220 (87.3)</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>21 (8.3)</td>
</tr>
<tr>
<td>Black/African American</td>
<td>8 (3.2)</td>
</tr>
</tbody>
</table>

Sample Characteristics

<table>
<thead>
<tr>
<th>Health Insurance Characteristics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance type</td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>188 (70.1)</td>
</tr>
<tr>
<td>Medicaid</td>
<td>43 (16.0)</td>
</tr>
<tr>
<td>Uninsured</td>
<td>37 (13.8)</td>
</tr>
</tbody>
</table>

Diabetes/Health Characteristics (N=267)

<table>
<thead>
<tr>
<th>Diabetes Characteristics</th>
<th>mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease duration in years</td>
<td>13.23 (4.52)</td>
</tr>
<tr>
<td>Provider type</td>
<td>n (%)</td>
</tr>
<tr>
<td>Adult</td>
<td>178 (67.7)</td>
</tr>
<tr>
<td>Pediatric</td>
<td>60 (26.2)</td>
</tr>
<tr>
<td>No Provider</td>
<td>16 (6.1)</td>
</tr>
</tbody>
</table>

Technology Usage

<table>
<thead>
<tr>
<th>Technology Usage</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insulin Pump</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>184 (68.7)</td>
</tr>
<tr>
<td>No</td>
<td>84 (31.3)</td>
</tr>
<tr>
<td>CGM Usage</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>152 (56.7)</td>
</tr>
<tr>
<td>No</td>
<td>116 (43.3)</td>
</tr>
</tbody>
</table>
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)

![Graph showing HbA1c distribution by sub-group.]

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

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.”
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."

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."

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."
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 I have 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."

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."

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."
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.

**DISCUSSION:**

**CLINICAL PRACTICE PEARLS**

**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
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

Resources

AADE Cost-Saving Resource Guide:

AADE Accessibility and Affordability Resources
https://www.diabeteseducator.org/practice/educator-tools/app-resources/affordability-resources

CONCLUSIONS
**Strengths & Limitations**

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very large N for qualitative</td>
<td>Cross-sectional</td>
</tr>
<tr>
<td>Generalizable across US</td>
<td>Bias - self-selected group, motivated due to study topic</td>
</tr>
<tr>
<td>Relevant, novel topic</td>
<td>Beginning stages of analysis (not a full thematic analysis)</td>
</tr>
</tbody>
</table>

**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

**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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References