“Everything is so expensive” – Financial Experiences of Adults with Type 1 Diabetes (T1D)

INTRODUCTION
- Annual personal healthcare costs for T1D are estimated at $2500 (private insurance) or higher.
- The economic burden of T1D may adversely affect quality of life.
- Despite attention to high costs of insulin in the popular press, little research has examined how adults with T1D experience the financial aspects of diabetes.
- Study Aim: to characterize perspectives of adults with T1D about diabetes-related financial issues.

METHODS
- Participants: 28 adults with T1D recruited from adult diabetes practices in Indiana (see Sample Demographics Table).
- Conducted semi-structured qualitative interviews about T1D-related quality of life, including questions about finances.
- Interviews were recorded and transcribed verbatim.
- Secondary qualitative analysis of financial-related experiences, using hybrid thematic analysis.

RESULTS
- Figure and interview excerpts on the right illustrate 4 themes and 14 subthemes identified through qualitative analysis.
- Perspectives on diabetes-related financial issues emerged in discussions about many domains of life (e.g., work, retirement, community, interpersonal relationships, etc.).
- Our sample was predominantly non-Hispanic white with private insurance. Different themes may emerge in a more ethnically and socioeconomically diverse sample.
- Greater advocacy is needed to improve access to affordable insulin, supplies, technologies, and health care.

DISCUSSION
- Costs of Supplies and Medication (e.g., affording insulin or glucose strips)
- Costs of Medical Services (e.g., doctor’s visit not worth the copay)
- Costs Guiding Treatment (e.g., using injections to avoid cost of insulin pump)
- Healthcare Industry (e.g., concerns about industry prioritization of profits over patient care)
- Financial Preparation (e.g., packing extra supplies for a long trip to avoid emergency purchases)
- Short-term Financial Impact (e.g., financial aspects of diabetes take time out of the day/redirects day)
- Long-term Financial Impact (e.g., costs interfering with saving money)
- Health Insurance (e.g., taking advantage of all annual health benefits under insurance plans)
- Employment Decisions (e.g., needing healthcare benefits through work)
- Awareness of Financial Inequities (e.g., acknowledging others’ access to devices can be financially challenging)
- Donating to Diabetes Causes (e.g., giving money to support diabetes organizations/research)
- Sharing Supplies (e.g., giving and receiving insulin, technology, or glucose strips)
- Financial Support From Others (e.g., spouse supporting financially/emotionally in handling large medical debt)
- Retirement (e.g., delaying retirement to keep healthcare coverage)

SAMPLE DEMOGRAPHICS

<table>
<thead>
<tr>
<th>Adults with T1D (n=28)</th>
<th>Mean±SD or %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years. Range=22-69</td>
<td>42.8 ± 15.9</td>
</tr>
<tr>
<td>Gender, Female</td>
<td>54%</td>
</tr>
<tr>
<td>Race/Ethnicity, Non-Hispanic White</td>
<td>92.8%</td>
</tr>
<tr>
<td>Insurance Status, Private or Private and Public</td>
<td>92.9%</td>
</tr>
<tr>
<td>Marital Status, Married or Partnered</td>
<td>53.5%</td>
</tr>
<tr>
<td>Pump Use</td>
<td>60.7%</td>
</tr>
<tr>
<td>A1c, %. Range=5.8-11.0</td>
<td>7.9 ± 1.17</td>
</tr>
</tbody>
</table>

HIGHLIGHTED EXCERPTS

COSTS OF DIABETES
- "I worry that I won't have the funds or the money to get my supplies, especially with, nowadays, economy and the healthcare system. I worry about that." 60 y.o. Male

HEALTHCARE COVERAGE
- "Who’s planning to retire? I need the insurance ‘cause from pump to pen needles, I gave away all my supplies, especially with… It’s kind of always hung in the back of my mind…" 27 y.o. Male

FINANCIAL IMPACT
- "I’ve always had this fear of not being able to afford my medication and it would cause my future children not to be able to eat or not live the way they want and stuff. It’s kind of always hung in the back of my mind…” 51 y.o. Female

PERSONAL AND COMMUNITY FACTORS
- "If I change meters I’ll give away my strips ‘cause they’re expensive. So, when I changed from pump to pen needles, I gave away all my insulin." 23 y.o. Female

Funded by The Leona M. and Harry B. Helmsley Charitable Trust (2015PG-T1D084) (Pis: Hilliard & Anderson). Complementary support from NIDDK 1K12DK097689 (Pis: Anderson)
“Everything is so expensive” – Financial Experiences of Adults with Type 1 Diabetes (T1D)

Objective: T1D is expensive to treat, and the lifetime economic burden may adversely affect quality of life. Despite attention to high costs of insulin in the popular press, little research has examined how people with T1D experience the financial aspects of diabetes. We characterized perspectives of adults with T1D regarding diabetes-related financial issues.

Methods: Secondary analysis of qualitative data from 28 adults with T1D (M age= 42.8±15.9, 54% female). Semi-structured interviews were transcribed and coded using hybrid thematic analysis.

Results: We found 4 major themes (Figure). Participants discussed high Costs of Diabetes and making financially-guided treatment choices, some detrimental to health (e.g., rationing insulin). T1D-related Financial Impact interfered with spending money across life domains (e.g., retirement, family needs). Participants stressed needing employment for Healthcare Coverage to afford medical expenses and reported frustrations with poor coverage. Many described Personal & Community Factors, such as awareness of inequities and sharing T1D-related financial support (i.e., monetary, emotional, supplies).

Conclusion: The financial aspects of T1D are all-encompassing and can impact treatment choices and other dimensions of life, like retirement planning. Greater advocacy is needed to improve access to affordable insulin, supplies, technologies, and health care.