Money Talks: Financial Aspects of Type 1 Diabetes and Parental Quality of Life

Sahar S. Eshtehardi MS¹, Viena T. Cao¹, Brett M. McKinney BS², Barbara J. Anderson PhD¹, David G. Marrero PhD², & Marisa E. Hilliard PhD¹
1. Baylor College of Medicine and Texas Children’s Hospital, Houston TX.
2. Indiana University School of Medicine, Indianapolis, IN.

BACKGROUND & AIDS

- Type 1 diabetes (T1D) management can incur substantial expenses. Average annual costs are estimated at approximately $6,000 (2005 value), plus additional costs for emergency room visits, hospital stays, medical devices, & missed work days (1).
- The rapidly rising cost of insulin has been regularly reported in the news, documenting many families’ struggles to access affordable T1D supplies & prescriptions (2, 3).
- Low socioeconomic status consistently predicts poor diabetes outcomes such as higher hemoglobin A1c, lower adherence, and more frequent hospitalizations (4, 5).
- However, little is known about the role of the financial demands of T1D on parents’ experiences and their quality of life.
- Better understanding the sources of parental stress such as issues related to finances, may improve pediatric psychologists care to youth with T1D.
- Thus, the aim of this study was to characterize the experiences of parents of youth with T1D in relation to care-related costs.

METHODS

- As part of a larger qualitative study on diabetes-related quality of life, 43 people (age 12-89 yrs.) with T1D and 37 of their parents or partners were interviewed.
- Interviews addressed many domains of quality of life including: social issues, mood, food & eating, as well as feelings about the costs of T1D care.
- Interviews were recorded and transcribed verbatim.
- Three psychologists and three research staff reviewed transcripts to develop thematic codes, which were applied using NVivo software (25% double-coded).
- A subset of 21 interviews with parents of children and adolescents (age 4-17 yrs.) were analyzed for themes related to financial demands of T1D.

RESULTS

Two primary themes emerged related to financial issues and managing T1D:

**Sacrifices**
- Parents describe making difficult decisions to accommodate T1D-related expenses, including making employment choices based on salary and insurance benefits.
- Many described prioritizing spending for T1D supplies, healthy foods, and medical bills, and forgoing spending related to parents’ personal needs and family vacations/recreation.

**Gratitude**
- Parents also discussed feeling thankful for insurance coverage and employment that offered benefits.
- Healthcare coverage helped alleviate or eliminate financial hardships associated with the cost of T1D management.

"Without my job, I wouldn’t be able to take care of her"
Parent of 11 y/o

"But without insurance I don’t even know how people would be able to do this. So in that, I feel fortunate"
Parent of 11 y/o

"It’s costly, but I thank God we have insurance"
Parent of 17 y/o

"We both have to work for financial reasons… I’m in a flexible job so I can leave when I need to and thankfully I have that”
Parent of 7 y/o

REFERENCES


*Research support from: The Leona M. and Harry B. Helmsley Charitable Trust (2015PG-T1D084 (PIs: Hilliard & Anderson) & NIDDK 1K12DK097696 (PI: Anderson) Questions or inquires may be directed to Marisa Hilliard, PhD at marisa.hilliard@bcm.edu or 832-624-7209.*