

MEASURING TRADE-OFFS: REPORTS FROM PEOPLE WITH TYPE 1 DIABETES REGARDING PROS VERSUS CONS WHEN CONSIDERING AN AUTOMATED INSULIN DELIVERY SYSTEM

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Background

The INSPIRE study (Insulin Delivery Systems: Perceptions, Ideas, Reflections and Expectations) is a multi-site study aimed at assessing the psychosocial experience of key stakeholders when using automated insulin delivery systems. The current sub-study analyzed focus group and interview data to assess perceptions regarding what burdens individuals with diabetes and their families were willing to tolerate in order to garner the hoped for benefits of an automated insulin delivery system.

Methods

Recruitment

Individuals 8 years old and older diagnosed with type 1 diabetes (PWD) for at least one year with no other chronic diseases were invited to participate with their parents or partners (N=284) at one of four study sites: Lurie Children's Hospital, Bournemouth University, Stanford University and Joslin Diabetes Center. Most of the PWD did not have experience automated insulin delivery systems, but rather shared their expectations for these new technologies.

Focus Groups and Interviews

Individuals participated in one of 48 age/role specific focus groups or in semi-structured interviews.

Coding

- Two coders from Lurie Children's reviewed transcripts from adults, teens, children, parents and partners for responses specifically addressing perceived benefits and burdens
- Compiled results were independently reviewed to identify salient themes for each benefit and burden
- Themes were consolidated after review and discussion among team members
 - Coding consolidation example: codes "automated insulin delivery system would accurately manage my diabetes" and "improving glycemic outcomes" combined to a united code "Improved Glycemic Control"
 - Saturation of themes was reached following review of 91 transcripts.
- Two coders from Bournemouth University independently coded 26 random transcripts to validate findings

Results

- Perceived benefits and burdens were consistent across the age/role groups. Identification was made of 10 benefits and 10 burdens

Descriptive Characteristics of Participants and Data Sources Means or percentages with ranges

Total number of participants, n	284
Adults with type 1 diabetes, n	113
Age, years (range)	39.5 (18-77)
Female	70.8%
Race/Ethnicity	
Black/African American	1.8%
Hispanic/Latino	0.9%
White, Non-Hispanic	92.0%
Other	0.9%
Bachelor's degree or higher education	73.5%
Current pump use	72.6%
Current CGM use	54.5%
Hemoglobin A1c	58 mmol/mol, (7.5%)
Parents of youth with type 1 diabetes, n	65
Relationship to youth	
Mother	79.7%
Father	17.2%
Other	1.5%
Youth's race/ethnicity	
Black/African American	1.5%
Hispanic/Latino	5.3%
Asian/Pacific Islander American	0.0%
White, Non-Hispanic	89.9%
Other	3.3%
Youth's current pump use	71.8%
Youth's current CGM use	53.5%
Youth's hemoglobin A1c	65 mmol/mol, (8.1%)
Adolescents/Young Adults with type 1 diabetes, n	35
Age, years (range)	14.7 (12-20.8)
Children with type 1 diabetes, n	16
Age, years (range)	10.3 (9-11)
Partners of people with type 1 diabetes, n	55

Perceived Benefits

Improve glycemic control

Improve quality of life

Improve night-time glycemic control

Reduce glycemic variability

More accurate bolus calculations

Reduce mental burden

Improve sleep

Improve long- and short-term health

Reduce daily management tasks

Perceived Burdens

Lack of connectivity of among system components

Cost or affordability of system

Hassle to find needed supplies

Concern about finding a knowledgeable provider

I believe I can do a better job than the system can

Change parts more frequently than I do currently

Still need to count carbohydrates

Spend extra time managing/checking the system

Wear multiple devices

Conclusions

- Perceived benefits and burdens were consistent across age and roles (person with diabetes, parent, partner).
- Many of the burdens were centered around tasks, time/costs associated with care.
- The perceived benefits reflected a desire for improved health and reduced mental burden.
- Findings highlight the importance of measuring the preferences of those will use this new technology.

