Influence of Psychosocial Factors on Interest in and Use of Automated Insulin Delivery Systems: Perspectives of Youth with Type 1 Diabetes and Their Parents

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Objective: To explore the influence of psychosocial factors on interest in and uptake of automated insulin delivery systems among children/adolescents with T1D and their parents.

Background and Methods: Automated insulin delivery systems will be more available and accessible in coming years. In order to optimize future uptake, we conducted a qualitative study, consisting of semi-structured interviews and focus groups, to understand patient and parent perspectives on whether and why they would use such automated systems. Across four sites in the United States and United Kingdom, 51 children/adolescents with type 1 diabetes and 65 parents of youth with type 1 diabetes participated. Data were transcribed verbatim and analyzed thematically.

Participants (n=116)	Age Mean (range)	A1c Mean (range)
Child (n=16)	10.3 yrs. (9-11 yrs.)	7.6% (7.0-8.0%)
Adolescent (n=35)	15.1 yrs. (12-20.8 yrs.)	8.7% (7.0-13.0%)
Parents (n=65)	Child's age: 12.8 yrs. (9.0-20.8 yrs.)	Child's value: 8.1% (6.4-13.0%)

Results: Descriptive characteristics of participants are presented in the table. Key themes identified were: 1) the unknown burden and benefits of the automated systems, 2) impact on quality of life and relationships, and 3) whether the system or youth would ultimately control decisions about insulin delivery. Children were most concerned with systems affecting specific social situations such as school and friendships. Adolescents were most interested in the physical features of the system, wearability, and time-savings. Whereas parents were most concerned about device safety, trade-offs, and the bumpy process of developing trust in a system. Exemplar quotes are presented below.

Children

"I think it would make it easier for me. But it depends what it does. If I still had to count carbs and everything, then it wouldn't really make a difference. But if I didn't have to count carbs, and I didn't have to do as many sugar tests, then I think it would make my life better."

"...if people saw it, I feel like they would make fun of me because I was made fun of for wearing a fanny pack. . .I'm fine with people knowing I have to carry stuff around, but making it visible just kind of makes me feel uncomfortable."

"Say your friend wants to get a snack, then I have to go somewhere separate to check my levels and give myself the shot. But if it's connected to me, I eat the ice cream and the medicine would already be in me."

Adolescents

"They [my parents] would probably worry the same amount, but I think if it controlled my blood sugar in the night and stuff they would be less worried and less tired."

"I kind of think it would be quite big, especially if there were wires and stuff connecting the pump to the cannula, and you have a sensor and a pump and the other gadget to carry around. I kind of think it would be quite heavy."

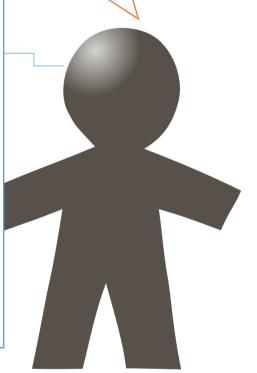
"if it is controlling my blood sugar and [my parents] are not having to look after it all the time and keep checking me all the time, I feel they would probably be more willing to let me go out by myself."

"I feel like it should be all an app, just one app on your phone."

Parents

"My expectation is for [a system] to relieve some of the burden; the cognitive burden that is on our kids of having to think and worry and plan and remember so much every day. And so far, that hasn't been realized in any of the studies that we've participated in...the real hope is that she will get to be more of a kid, and have to deal with fewer decisions every day."

"...if there's information somewhere that can go real time, to me as a parent, that would be enormously helpful because [my] son can perhaps sleep through an alarm. . .having access to information that's on their pump now—if a carer, can have that. Then that's an enormous failsafe. That would make a big difference."



Conclusion: Incorporating stakeholder perspectives on use of automated insulin delivery may improve adoption, health outcomes, and quality of life indicators among users. Efforts are needed to build trust in systems, optimize device interactions, and provide clear guidance on use in order to maximize uptake and sustained device use.

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