Experiences of user-led diabetes technologies among Australian adults with type 1 diabetes

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BACKGROUND
• An emerging group of adults with type 1 diabetes are building their own artificial pancreas systems (e.g., AndroidAPS, OpenAPS, Loop).
• These systems are currently not endorsed by regulatory bodies.
• Early research shows improvements in glucose levels, but further research is needed into impact on quality of life, and the challenges that people face building and using these systems.1
• Exploring these experiences will help us understand user-led healthcare solutions in broader contexts.

AIM
• Our aims were to explore:
  a) the experiences of user-led systems among adults with type 1 diabetes,
  b) any challenges encountered, and
  c) how they overcome such challenges.

METHODS
• Semi-structured telephone interviews were conducted and analysed thematically.

RESULTS
• N=23 Australian adults were interviewed:
  • median age: 46 (range: 25-64) years, 10 women
  • n=21 previously using insulin pump, n=23 using continuous glucose monitoring
  • experience with user-led systems: >12 months: n=8, 6-12m: n=6, <6m: n=9
• Themes, sub-themes and illustrative quotes from participants are shown below.

Benefits
Compared to previous management:
• More stable glucose levels
• Better sleep quality
• Reduced psychological burden

Challenges
• Technical and financial issues (associated with building their system)
• Being unable to seek support from healthcare professionals or industry
• Own/others’ perceptions of risk

Overcoming Challenges
• Empowerment gained from building own system
• Seeking out support from others (e.g. peers using ‘user-led’ systems and family members)

Benefits
Reduced Psychological Burden
“There is natural stress associated with being a diabetic, the constant decision-making, the constant things beeping at you, the constant having to think in advance. This just helps you take one of those stresses.”
ID 12, 42 yrs

GLUCOSE LEVELS
If you’d asked me 3 years ago to try and keep between 4.3 and 7.6 I would have laughed in your face. Today I know that it’s a reality and I know that it’s really done.”
ID 12, 42 yrs

Glucose Levels
• Occasionally things go wrong. Occasionally an insulin pump cannula becomes blocked or a CGM sensor starts to go weird and the calibration goes off or it doesn’t respond.”
ID 6, M, 30 yrs

Technical Challenges
“Occasionally things go wrong. Occasionally an insulin pump cannula becomes blocked or a CGM sensor starts to go weird and the calibration goes off or it doesn’t respond.”
ID 6, M, 30 yrs

Lack of Support: Industry
“If it was a commercially available system, you wouldn’t have to worry about (continually updating software). You’d just trust that the developers have done the software correctly... Whereas, when you’re doing it DIY, you’ve got to invest a bit more time and effort into actually building the software.”
ID 10, M, 54 yrs

Risk
“There’s an element of risk that things don’t go as planned, because it’s not really set up with official channels for support or recompense.”
ID 13, M, 46 yrs

Overcoming Challenges
Empowerment
“In 34 years of living with type 1 diabetes it’s the very first time that I’ve felt absolutely in control of what's happening.”
ID 6, 47 yrs

Peer Support: Technical
“That’s really, really useful and helpful and when you get yourself into a pickle, there’s always somebody that can help...point you in the right direction. Like, actually you need to swap that sensor.”
ID 13, M, 46 yrs

Peer Support: Confidence
“Three people I knew and respected and trusted were all looping and I thought oh well if they’re doing it then there’s...been enough guinea pigs so I’m willing to give it a try now.”
ID 19, F, 39 yrs

CONCLUSIONS
• Most participants felt that benefits of user-led technology outweighed challenges. They were able to navigate challenges due to support (especially from peers), and the empowerment gained from building their own system.
• A strength of this research is that most participants were early adopters; while a limitation is that they may not be representative of the wider community of (potential) users of this new diabetes technology.

REFERENCES

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