The “helping dilemma”: Experiences of parents and partners of people with type 1 diabetes (T1D) across the lifespan

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ABSTRACT

Objective: Given the many demands of T1D self-management, the benefit of support from family members is well-documented. Yet the ideal roles for parents and partners in T1D management at different ages are not clear and may cause strain within families. Provider awareness of challenges challenges parents and partners experience in finding the balance between helping and intruding can inform clinical efforts to facilitate family teamwork for T1D management.

Methods: As part of a larger qualitative study on diabetes-related quality of life, 23 parents and 13 partners of youth and adults with T1D were interviewed. Interviews addressed many aspects of their quality of life in relation to having a loved one with T1D, including their roles in T1D management.

Example interview questions on this topic:
- How does your family manage your teen’s diabetes? Who does what?
- What do you found works well for your family diabetes management? How could it be better?
- In what ways, if any, are you involved in your partner’s diabetes management?
- How do you feel about your role in diabetes management?
- What is communication about diabetes like in your family?
- Interviews were recorded and transcribed verbatim before coding.
- Three psychologists and three research staff reviewed transcripts to develop thematic codes, which were applied using NVivo software (25% double-coded).

RESULTS

- Parents and partners both described the “helping dilemma”, characterized as their uncertainty about how much and in what ways to participate in their child/partner’s T1D management.
- In some cases, the person with T1D resisted their involvement and in others participants were unsure how much involvement was appropriate.

METHODS & PARTICIPANTS

- Awareness of their adolescent’s need to develop independent self-management skills, contrasted with worries about the risks of being under-involved.
- Balance of providing adequate support for T1D management and fostering autonomy and responsibility within their child.

Parents

"I don’t want to be that helicopter parent, either. I want her to have some autonomy"
Parent of 11 y/o

"It’s his sickness and I do want to feel that he’s in control of it, so I’m just on the sideline looking to make sure he doesn’t mess up"
Parent of 14 y/o

"She’s gonna be on her own and I have to ensure she’s gonna be able to take care of herself"
Parent of 15 y/o

"He resents me for reminding him to check his blood glucose levels"
Parent of 23 y/o

Partners

"He [says he] knows best how to take care of himself"
Partner of 36 y/o

"But then like with anything, you have somebody sitting there more constantly asking you about it, it’s just gonna get old and you’re not gonna wanna do it anymore"
Partner of 36 y/o

"I think sometimes it’s difficult not to overstep and allow him to be the person who’s managing things"
Partner of 58 y/o

"She’s always really wanted to do it herself, she’s never wanted people looking over her shoulder about it. Probably concerned that we’d start telling her how to do it or what she should be doing"
Partner of 68 y/o

CONCLUSIONS

- As people with T1D gain more self-management autonomy, the role of parents/partners becomes less clear and can become a source of conflict.
- Parents and partners of people with T1D often have uncertainty about the amount and type of support to offer, and the boundaries of their roles.
- Known as the “helping dilemma”.
- Evolves and shifts from childhood through adulthood.
- Clinical discussions related to the helping dilemma may address:
  - Understanding the needs and wishes of the person with T1D and their family members
  - Facilitating family support that meets everyone’s needs
  - Identifying supportive roles for family members that respect the autonomy of the person with diabetes
  - Providing additional resources, in some cases referrals to mental health providers
  - Diabetes care providers that acknowledge and address the helping dilemma may help people with T1D and their families improve management and quality of life.

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