

Perspectives of Parents With Type 1 Diabetes: Role of Children in Self-Management and Support



Jodi Krall, PhD 

Vicki S. Helgeson, PhD

Eunjin Lee Tracy, PhD 

MaryJane S. Campbell, MS

Mary Korytkowski, MD

Cynthia A. Berg, PhD

From University of Pittsburgh Diabetes Institute, Pittsburgh, Pennsylvania (Dr Krall); Psychology Department, Carnegie Mellon University, Pittsburgh, Pennsylvania (Dr Helgeson); Department of Psychiatry, University of Pittsburgh, Pittsburgh, Pennsylvania (Dr Tracy); Department of Psychology, University of Utah, Salt Lake City, Utah (Mrs Campbell; Dr Berg); and Department of Medicine, University of Pittsburgh, Pittsburgh, Pennsylvania (Dr Korytkowski).

Correspondence to Jodi Krall, PhD, University of Pittsburgh Diabetes Institute, 4401 Penn Ave, LMB, Room 2113, Pittsburgh, PA 15224, USA (jodi.krall@chp.edu).

Conflicts of Interest: The authors declare that there is no conflict of interest.

Acknowledgments: The authors would like to express their gratitude to the participants and staff for their involvement with this study. This material is based on research sponsored by the NIH NIDDK DP3 DK103999.

DOI: 10.1177/0145721720964598

© 2020 The Author(s)

Purpose

The purpose of this study was to examine parents' perceptions of the role children play in their type 1 diabetes (T1DM) care. Family members are a resource to support T1DM self-management, but how children are involved in their parents' diabetes has not been well explored.

Methods

Parents with T1DM ($n = 85$) and a subset of their romantic partners ($n = 55$) participated in interviews during which they described their children's knowledge of and involvement in diabetes care. Interviews were transcribed, responses coded/tallied, and themes identified.

Results

All parents reported that children knew of their diabetes, which they learned about progressively from a young age. Most parents reported children to be accepting and understanding of the ways that diabetes affected their family experiences (eg, pause to treat low blood glucose). When asked about specific support, parents rated "making parent feel better about diabetes" as the most frequently occurring behavior. Some parents felt that children, particularly younger ones, occasionally detracted from T1DM management, but this was usually expected and considered transient. Regardless of child age, many parents did not want diabetes to burden children and limited their involvement. Both parents with T1DM and partners

requested resources to enhance child awareness and preparedness to support diabetes. Respondents, particularly partners, were also interested in learning how to communicate better as a family and share perspectives on how diabetes affects individual family members.

Conclusions

Diabetes care and education specialists should consider developmentally and relationally appropriate ways to engage children of parents with T1DM in education and self-management.

.....

Type 1 diabetes (T1DM) is a complicated and demanding condition that requires a complex array of behaviors that need to be executed on a daily basis to achieve optimal glycemic control.¹ The family is recognized as an important resource to support individuals in their self-management.^{2,3} Although there is a large literature demonstrating the importance of family support for diabetes self-management among children with T1DM,^{4,5} there is much less research on the role of the family among adults with T1DM. There is an emerging literature on family support for adults with T1DM that largely focuses on the benefits of partner support for self-management as well as psychological health.⁶ However, less is known about the role of children in parents' diabetes self-management—in particular, young children who are living in the home with parents.

It is not clear what children know about their parents' T1DM management. Family communication about T1DM could be implicit or explicit. Children may become aware of their parents' diabetes at an early age through direct observation of the daily self-care behaviors that are visible (eg, checking blood glucose, injecting insulin), presence of equipment in the home (eg, blood glucose meters, pumps, continuous blood glucose monitors), or hypoglycemic events that require intervention. Because parents try to shield their children from the daily burden of T1DM,⁶ it is not clear whether children have adequate information to provide the kind of support that parents would find helpful.

Some research shows that children are both sources of support and sources of difficulties with T1DM self-

management.^{6,7} Children can provide direct assistance on a daily basis by getting diabetes supplies, reminding to check blood glucose (BG), exercising with parents, and seeking help for low blood sugars in the case of an emergency. Children also serve as an indirect source of support by motivating parents to take better care of their diabetes. By contrast, children also can directly detract from diabetes self-management because children have needs to which parents must attend and parents often put children's needs before their own. Children can indirectly serve as a distraction from self-care when time with children seems more rewarding than self-care or parents worry that self-care is upsetting for children. For example, a study showed that some adults with T1DM missed taking insulin or BG checks because they needed to attend to their children and that other adults with T1DM reported less than optimal self-care because they did not want to scare their children with their regimen.⁶ A study of adults with type 2 diabetes showed that children's diets sometimes served as temptations for poor self-care.⁸ Given the relative lack of research on the role of children in parents' diabetes management, research into this area is warranted.

The purpose of the present study was to explore the perceptions that parents with T1DM have about their children's knowledge of diabetes and the role their children play in diabetes self-management and support.⁹ This objective was addressed through qualitative interviews with adults with T1DM and their partners who had children in their home.

Methods

Sample and Setting

This cross-sectional qualitative study was conducted with a subsample of individuals who had participated in a study examining partner involvement in diabetes. For the larger study, adults, ages 25 and older, who had been diagnosed with T1DM for at least 1 year and living with or married to a romantic partner without diabetes for at least 1 year ($n = 199$ couples) were recruited from outpatient endocrinology clinics at 2 large, urban-based, academic hospitals. At completion of the larger study, research assistants telephoned and invited all couples who had children ages 2 years or older that were currently or previously living in the same household as the parent with T1DM to participate in the present study. A total of

Table 1

Participant Characteristics

Characteristic	Persons With T1DM (n = 85)	Partners (n = 55)
Race	97.6% white	96.4% white
Sex	54.1% female	45.5% female
Age, y	50.8, range = 27.3-74.6	46.4, range = 23.9-76.7
Marital status	97.6% married	91.4% married
Length of DM diagnosis	29.80 y, SD = 12.80	—
Pumps and CGM	76.5% on insulin pumps 42.4% on CGM	—
Abbreviations: CGM, continuous glucose monitoring; DM, diabetes mellitus; T1DM, type 1 diabetes.		

85 parents with T1DM who had children and 55 of their romantic partners agreed to participate and completed interviews; their characteristics are provided in Table 1. On average, couples had 2 children. Only 4 couples had a child with T1DM. For couples with both members participating in the interview, their average length of relationship was 25.6 years (range = 4-52). Because the vast majority of couples were married, the term *spouse* is used to refer to partners. The study was approved by the institutional review boards of Carnegie Mellon University, the University of Pittsburgh, and the University of Utah.

Data Collection

Audio-recorded telephone interviews, lasting 20 to 60 minutes, were conducted with each participant. Telephone (vs in-person) interviews were chosen to reduce participant burden. Trained interviewers followed a semistructured interview guide that was organized into the following sections: (1) background information about family—questions about number and ages of children, relationship of children to parent with T1DM, and current living arrangements; (2) awareness of diabetes—do children know parents have diabetes, how did children find out about diabetes, how old were children when they found out, and what did parents tell/not tell children about diabetes; (3) knowledge of and experiences with specific diabetes topics, including high and low BG and glycemic events; (4) effect of parent's diabetes on children—how does parent's diabetes affect children, do children express worry or concerns, and how children help or detract from diabetes care; and (5) level and types

of involvement children have with their parent's diabetes care. Sample questions are listed in Table 2. Most questions were directed to all children that the parent with T1DM and/or spouse had collectively, but some questions were asked about each of the children up to a maximum of 6. An interviewer transcribed recordings within 2 week of completing the interview.

Data Analysis

Data analysis was informed by grounded theory¹⁰ and followed a thematic analysis approach.¹¹ An experienced lead researcher first read through interview transcripts to become familiar with and organized them. Transcripts then were iteratively examined within and across respondents to identify, code, and construct themes. During the process, the lead researcher reviewed and reconciled findings with other members of the research team. Analysis continued until consensus was reached.

Results

Key themes about the relationship between children and their parent's T1DM emerged from the interviews with parents with T1DM and their spouses and are described in this section.

Children Progressively Learn About Their Parent's T1DM

All parents reported that children knew of their T1DM, which children generally learned about progressively from a young age. For example, a parent said: "Since

Table 2

Sample Interview Questions

Do your children know that you have type 1 diabetes? [If no, is there a reason why you haven't told them?]

- a. How did your children find out that you have diabetes?
- b. About how old were they when they found out?
- c. What specifically did you tell them about diabetes?
- d. Is there anything that you didn't tell them?
- e. Have you experienced any complications from diabetes? *If yes*, do your children know anything about this?
- f. Have you come across any misperceptions your children have about diabetes—things that are not true that they believed for some reason?

I am going to ask you about how much each of your children know about some specific topics. How much do your children know about:

- a. Signs of low blood sugar
- b. Signs of high blood sugar
- c. How to treat low blood sugar
- d. How to treat high blood sugar
- e. What to do in an emergency when your sugar gets really low
- f. How your pump/continuous glucose monitor works

Now I would like to ask you some questions about how diabetes affects your children. (These questions are about current relationships with children.)

- a. In what ways does having diabetes affect your children?
- b. Do your children express any worries or concerns about your diabetes?
- c. Are there any ways in which your children help you with diabetes on a daily basis or just living with diabetes?
- d. Are there any ways in which your children make it more difficult to take care of your diabetes or just to live with diabetes?

I am going to list some specific behaviors, and I want you to tell me how often your children overall have done each of these in the past year.

- a. Helped you check your blood sugar
- b. Reminded you to tend to your diabetes—check your blood sugar or take insulin
- c. Suggested your blood sugar was low or high when it was NOT
- d. Called someone for help because you needed it
- e. Gone to a doctor's appointment with you and went into the room with the doctor
- f. Carried food with them in case you needed it for a low blood sugar
- g. Told you that you shouldn't eat something because of your diabetes
- h. Noticed that your blood sugar was low
- i. Gotten you something to eat or drink because your sugar was low
- j. Made you feel better about your diabetes

they were born, they just knew that was part of who mom was." Initial awareness often occurred in the context of witnessing BG checks and seeing diabetes-related devices. Another parent with children ages 2 and 4 years said: "They see me take my blood sugar, adjust my pump, things like that."

Many noted that there was not a conscious decision to disclose diabetes. For example, a parent said: "It is not like we sit them [our children, ages 2, 4, 7, and 9 years] down at a time and, 'By the way, dad has this.' Even our youngest, technically, has been told or is being told throughout life. Its more just when they are mentally able

to comprehend what that means.” During initial discussions, parents typically did not withhold information from their children; those who did reported that they omitted details about the potential for severe complications and death. Comments ranged from “I don’t share with them worries or concerns I have” to “I didn’t tell them that I could die from having low blood sugar, or anything gruesome.”

Diabetes Knowledge Is Gained Experientially

Children often learned about diabetes from observing parents’ diabetes self-management or treatment of parents’ diabetes-related problems. This was particularly true, and most often described, with regard to hypo/hyperglycemia. For example, a parent said: “They’ve seen me be hypoglycemic and say I need to eat glucose tablets. They’ve learned from that.” Some parents mentioned that children learn the signs of low BG, as one parent reported: “My oldest [9 years] is to the point where he’s heard [his] mom ask certain questions, so he’ll follow up with them, ‘Dad you look this way,’ or ‘Are you going low?’ So, he’ll ask the questions.”

Child knowledge of glycemia, as reported by parents, corresponded with the type, frequency, and severity of glycemic occurrences. Children were more aware of the signs of and how to treat low BG than high BG presumably because hypoglycemia was easier to identify than hyperglycemia. This is reflected in the following statement: “Sometimes they’ll ask, ‘If dad gets really low . . .’ Just the other day, our [8-year-old] asked, ‘What happens if dad’s blood sugar gets really high?’” These findings were consistent across children of various ages.

Children Serve as Facilitators and Barriers to Diabetes Self-Management

Overall, children were not very involved in their parents’ diabetes. When asked to rate their level of involvement on a 4-point scale, with 1 signifying not at all and 4 signifying a lot, the means for each child were around 2 points. However, parents reported children to be accepting and understanding of the ways that diabetes affected their family. One mother of a 3-year-old said, “[My son] understands if I say, ‘Mommy has to do this before we go,’ he doesn’t complain at all. He just accepts that’s what needs to be done.” When asked about which diabetes-related tasks children perform, parents rated “making

parent feel better about diabetes” as the most frequently occurring behavior. For example, a parent with 5 adult-age children stated, “They ask me how I feel, how I’m doing with [diabetes]. They don’t really talk about it much, but they are supportive.” Similarly, another parent said of his 3 adult-age children, “They don’t really help me, but I would say that they’re concerned and their confidence in my own grasp and ability to handle the condition is helpful to me.”

Some parents expressed that children, particularly younger ones, occasionally detracted from T1DM self-care. For example, a father said, “Because [children, ages 2 and 4] are so young, it’s hard for me to do all of my checking and insulin delivery. If I’m really busy with them or if my wife isn’t home or around, then I usually take care of my kids first, and sometimes I forget to do insulin and things like that.” At the same time, respondents acknowledged that the ways in which children might distract from or interfere with diabetes management was generally expected: “Diabetes is a full-time job and so is a 2-year old.” The potential interference was also considered transient, as a parent of 2 teenagers, ages 16 and 18 years reflected: “When they were little, they took a lot of time and I probably let things fly that I shouldn’t have let fly. But now, no. Not as old as they are now.”

Parents Limit Children’s Involvement in Diabetes Self-Management

Regardless of child age, many parents limited children’s involvement in diabetes care because they did not want to burden them. As one parent reported, “Even though my kids are living in a home where someone has a chronic illness condition, I want you [interviewer] to know that I’ve done my best to keep their childhood as normal and typical as possible.” Similarly, another parent stated, “I don’t want my diabetes impacting their lives to a great extent. And then sometimes if my sugar gets low, I just know how to treat it, but it didn’t affect anything other than me trying to get something to eat at that point.”

Availability of spousal support likely influenced child involvement in diabetes management. Some parents with T1DM reported that they primarily depended on their spouse to assist with diabetes-related needs. For example, when asked about the ways her children are involved with diabetes care, a mother of 3 children, ages 11, 22, and 27 years, responded, “My husband is my go-to person, so he would be the person that would go with me to appointments or see where my blood sugar is, things like

that.” A similar sentiment was expressed by a spouse who said, “My husband really needs help sometimes, especially from me, but he really shields the children from it. I think he really doesn’t want to burden them with it or make them worried about it.”

A parent’s ability to properly manage his or her diabetes and keep it well controlled was also identified as a reason for limited child involvement. This reason was more frequently reported by the spouse rather than the parent with T1DM. For example, a father with children ages 7, 12, and 21 years stated, “[The children] are all semi-involved, but not really. My wife does a really good job keeping everything in control. The only thing they’ve probably had to help with is grab a juice box when she’s low.” Likewise, a parent with 2 adult children, ages 33 and 35 years, reported, “My wife does an outstanding job of managing her diabetes, and so there really isn’t a need for input from the kids. If it were important that [they] were involved, they would be.”

In addition, newer technology, particularly continuous glucose monitoring (CGM), seemed to limit children’s involvement in self-care because of their stress-reducing properties. As explained by one father, “I think [my children, ages 18, 21, and 25 years] were more vigilant before I got the CGM. It was more stressful. [My children] had to worry more about is everything okay with dad? Is he going to be alright when we go do this? And now it is less stressful because of the CGM. I couldn’t tell when I had low blood sugar before.”

Family Education and Support Resources Are Needed

Respondents requested resources to enhance child awareness and preparedness to support parents with T1DM. As expressed by a parent of young children, “If I could wave a magic wand, I would want [my children, ages 1 and 5 years] to understand [diabetes] fully and know how to explain it to them in the right ways for their ages.” In terms of devices, a spouse stated, “We all need to be educated on [insulin pump]. It’s easy to tell if [my wife] is low, but not as easy if [her blood sugar] is high.” Parents with T1DM, and more so their spouses, also expressed an interest in learning how to better communicate as a family and share perspectives on how diabetes affects individual family members. A mother/spouse with an adult daughter, age 21 years, suggested, “If my daughter knew [her father’s] blood sugar, or even if we had a

family meeting once a month, ‘What’s going on with dad?’ That would be helpful.” Another spouse stated, “I want [my husband] to talk more about [diabetes] with [the children]. He’s very private about his diabetes.” In addition, there appeared to be a need to address the genetic susceptibility of diabetes given that 40% of parents with T1DM ($n = 33$) expressed a concern that their children would develop T1DM. A mother of a 1-year-old daughter shared, “I watch continuously for signs of diabetes. I test [daughter’s] blood sugar whenever she has a cold or a sniffle, just because I want that off my mind.”

Discussion

The results of this study show that children of parents with T1DM are generally aware of the disease. However, this awareness seems to occur in response to the passive observing of routine diabetes self-care tasks or even in response to witnessing diabetes difficulties, most notably hypoglycemia. Observing T1DM self-management and/or difficulties may not be the optimal way to educate children about diabetes and its management. Particularly if parents are interested in shielding children from the distress and worry attached to diabetes, they might be better served by resources that enable them to discuss diabetes and its self-management prior to witnessing any adverse events.

Research on educating children about other chronic illnesses such as cancer indicate that children benefit when they receive information about their parent’s chronic illness and how to support their parent.¹² Children typically form their own views about the seriousness of an illness, and these perceptions are often more severe than is warranted from illness diagnosis and treatment.¹² Education may be helpful in preventing children from developing misconceptions about diabetes. Greater family education and communication about T1DM may not only empower children to assist when needed in their parent’s care (eg, calling 911 with a severe hypoglycemic event) but also to help them to understand their own risk for future diagnosis of T1DM.

Parents also seem to be concerned with ensuring their children have a normal childhood and do not have to assume any responsibilities for diabetes management. This concern with burdening children also arises in the context of adult relationships¹³ and has been noted in other qualitative studies of families with a member with T1DM.⁶ These concerns may prevent parents from talking to

their children about diabetes, with the potential consequence that children might be less informed, less equipped to help, and more worried about something they do not understand well. Given these possible outcomes, future research should investigate the extent of children's knowledge and understanding of diabetes.

Although the children in this study seemed to be less directly involved in diabetes management, parents expressed that children were an important source of emotional support. Parents valued their children's acceptance and understanding. This emotional support is likely to not only enhance parents' psychological well-being but also motivate to enact good self-care.

Children also posed barriers to self-care, especially when they were younger. As discussed by previous research,⁶⁻⁸ children can serve as a distraction from diabetes self-care because parents prioritize children's needs over their own. It is during these times that spouses may be particularly helpful. In fact, parents often reported that they need not rely on children because they had spouses as available supporters. The implications of this finding for single parents or parents who may become separated or divorced over time remains to be determined.

The conclusions drawn from this study are limited in that the majority of parents were white, well educated, and living with a romantic partner/spouse, making it unclear how diabetes affects children in families with fewer resources. It is also the case that only a subset of partners participated. In addition, the views of the children were not represented in this study. Future researchers should interview children to determine if the views expressed by parents are shared by their children.

Implications for Diabetes Care and Education Specialists

Diabetes care and education specialists should consider developmentally and relationally appropriate ways to engage children of parents with T1DM in education and self-management.

ORCID IDS

Jodi Krall  <https://orcid.org/0000-0002-9798-0345>

Eunjin Lee Tracy  <https://orcid.org/0000-0002-8610-1464>

References

1. Beck J, Greenwood DA, Blanton L, et al. 2017 National standards for diabetes self-management education and support. *Diabetes Educ.* 2020;46(1):46-61.
2. Miller TA, Dimatteo MR. Importance of family/social support and impact on adherence to diabetic therapy. *Diabetes Metab Syndr Obes.* 2013;6:421-426.
3. Wiebe DJ, Helgeson V, Berg CA. The social context of managing diabetes across the life span. *Amer Psychologist.* 2016;71(7):526-538.
4. Berg CA, Butner J, Wiebe DJ, et al. Developmental model of parent-child coordination for self-regulation across childhood and into emerging adulthood: type 1 diabetes management as an example. *Dev Rev.* 2017;46:1-26.
5. Helgeson VS, Palladino DK. Implications of psychosocial factors for diabetes outcomes among children with type 1 diabetes: a review. *Soc Personal Psychol Compass.* 2012;6(3):228-242.
6. Rintala TM, Paavilainen E, Åstedt KP. Everyday life of a family with diabetes as described by adults with type 1 diabetes. *Eur Diab Nursing.* 2013;10(3):86-90.
7. Gunn KL, Seers K, Posner N, Coates V. "Somebody there to watch over you": the role of the family in everyday and emergency diabetes care. *Health Soc Care Community.* 2012;20(6):591-598.
8. Laroche HH, Davis MM, Forman J, et al. Children's roles in parents' diabetes self-management. *Am J Prev Med.* 2009;37(6 suppl 1):S251-S261.
9. Helgeson VS, Berg CA, Kelly CS, et al. Patient and partner illness appraisals and health among adults with type 1 diabetes. *J Behav Med.* 2019;42(3):480-492.
10. Strauss A, Corbin J. Grounded theory methodology: an overview. In: Denzin NK, Lincoln YS, eds. *Handbook of Qualitative Research.* Sage Publications, Inc; 1994:273-285.
11. Guest G, MacQueen KM, Namey EE. *Applied Thematic Analysis.* Sage Publications, Inc; 2012.
12. Ellis SJ, Wakefield CE, Antill G, Burns M, Patterson P. Supporting children facing a parent's cancer diagnosis: a systematic review of children's psychosocial needs and existing interventions. *Eur J Cancer Care.* 2017;26(1). doi:10.1111/ecc.12432
13. Helgeson VS. Young adults with type 1 diabetes: romantic relationships and implications for well-being. *Diabetes Spectr.* 2017;30(2):108-116.