



# Adolescent and Parent Perceptions of Long-Term Type 1 Diabetes Complications

Michelle L. Katz, Tara Kaushal, Zijing Guo, Alina Cheema, Rachel Gerrard, and Lori M. Laffel

*Joslin Diabetes Center, Boston, MA*

**AIMS** | Conversations about diabetes complications with adolescents and parents can be difficult and emotionally charged. To better inform conversations between providers and families, we sought adolescent and parent perspectives regarding their knowledge of long-term complications (LTCs), where they receive this information, and what they would like to learn from clinicians.

**METHODS** | Adolescents with type 1 diabetes and parents of adolescents with type 1 diabetes participated in semi-structured interviews querying knowledge of LTCs, sources of information, and preferred ways for providers to discuss LTCs. Interview transcripts were coded and categorized into central themes by content analysis.

**RESULTS** | Participants included 22 adolescents (17.4 ± 1.7 years of age, diabetes duration 9.7 ± 4.0 years) and 25 parents (41–60 years of age, 84% mothers). Five themes related to complications were identified: 1) “Limited Adolescent Knowledge of Complications,” 2) “Discussing Complications Is Important but Not Now or Not for Me,” 3) “Outside Sources Overestimate Risk,” 4) “Avoid Scare Tactics” and 5) “Emphasize Prevention.” Adolescent and parent perspectives were similar, although parents showed greater understanding of complications.

**CONCLUSION** | When discussing complications, individualized, factual, positive, and prevention-focused conversations may be better received by adolescents with type 1 diabetes and their families.

Pediatric diabetes care tends to focus on developing habits aimed at promoting optimal glycemic control and avoiding acute complications, with limited focus on chronic complications. The desire to reduce risk of future chronic complications may not be fully addressed in conversations with adolescents and families, although it may provide context for the focus on adherence and improving glycemic control. Past research has shown significant practice variation among pediatric providers with regard to counseling adolescent patients and their parents about long-term complications (LTCs) of diabetes (1,2), although most providers feel it is their responsibility to provide detailed information about these complications to adolescents and their parents (1).

Past studies have assessed some aspects of adolescent and parent perspectives on LTCs. In terms of youth alone, a study exploring illness perceptions of adolescents with well-controlled type 1 diabetes found participants to report knowledge of long-term negative health consequences and that these consequences were often associated with poor diabetes control (3). An analysis of risk perception and

regimen adherence in minority adolescents with type 1 diabetes found that adolescents perceived themselves and others to be at significantly greater risk for short-term complications rather than for LTCs; additionally, these adolescents perceived that others with type 1 diabetes would have a higher chance of developing LTCs than they would themselves (4).

Other studies have included both parents and adolescents. For example, from a qualitative study designed to inform application development for type 1 diabetes support, it was found that both parents and children worried about the future; however, the parents thought their children were not worried and that youth themselves felt alone in their worries and reported keeping these worries private (5). Using structured interviews of parents and adolescents, Wysocki et al. (6) found that, although youth's knowledge of and frequent, optimistic discussion with family members about LTCs predicted better adherence to type 1 diabetes treatment, parental knowledge was not associated with any type 1 diabetes outcomes. This same group developed an

Corresponding author: Michelle L. Katz, [Michelle.Katz@joslin.harvard.edu](mailto:Michelle.Katz@joslin.harvard.edu)

<https://doi.org/10.2337/ds20-0042>

©2020 by the American Diabetes Association. Readers may use this article as long as the work is properly cited, the use is educational and not for profit, and the work is not altered. More information is available at <https://www.diabetesjournals.org/content/license>.

Internet-based survey of just parents of children with type 1 diabetes and showed that parents were most likely to report that they and their children had not received adequate information about LTCs and that they most commonly obtained information on LTCs from the Internet, physicians, and diabetes magazines. Responses about how education about LTCs should be adjusted based on age varied significantly in this group, although most parents agreed that their own education should begin at diagnosis (7).

There remains a need for a study directly investigating both adolescent and parent knowledge of and perspectives on diabetes LTCs, as well as whether, when, and how they would like additional information on LTCs from their providers. Understanding the viewpoints of adolescents with type 1 diabetes and their parents with regard to counseling on LTCs can help diabetes providers thoughtfully frame conversations in ways that are better received by adolescents and families, therefore potentially preventing these complications later in life.

In this study, we aimed to describe adolescent and parent knowledge, opinions, and beliefs regarding LTCs. We conducted semi-structured interviews with adolescents with type 1 diabetes and parents of adolescents with type 1 diabetes to describe their perceptions of LTCs, information sources, and needs for information regarding LTCs from their diabetes providers.

## Materials and Methods

### Participants

Adolescents (13–19 years of age) with type 1 diabetes for at least 1 year and parents of an adolescent with type 1 diabetes for at least 1 year were eligible to participate in the study. Adolescents and parents did not need to be a parent-child dyad to participate. Participants were excluded if they were enrolled in an intervention study.

Adolescents with dyslipidemia were identified before enrollment to ensure a sample that included adolescents with previous exposure to risk factors for LTCs such as cardiovascular disease for the purpose of exploring heart-healthy behaviors among the adolescents (8). Dyslipidemia was defined by diagnosis of dyslipidemia found in the adolescent's electronic health record. Typically, this diagnosis indicated a current or previous elevation in LDL cholesterol levels.

Participants provided informed assent/consent prior to study participation. The study was approved by the Joslin Diabetes Center institutional review board.

### Recruitment

Participants were recruited on the day of their regular clinic visit at a single diabetes center to compose a convenience cohort. Participants completed a questionnaire to provide demographic information. Recruitment continued until no new potential themes were uncovered by the interviewer and primary investigator in several consecutive interviews.

### Data Collection

A team of pediatric diabetes physicians, pediatric psychologists, diabetes nurse educators, data analysts, and research assistants developed the interview script. The script consisted of open-ended questions with probes as needed to encourage full responses from participants. Interviewers received training in qualitative methods, including how to encourage an open dialogue without biasing responses.

Participants were first asked about heart-healthy knowledge and behaviors and then about diabetes complications generally. The researchers conducted separate semi-structured interviews for parents and adolescents. The interviews lasted 15–60 minutes each and were completed either in person ( $n = 28$ ) or by phone ( $n = 19$ ). The interviews were recorded for transcription.

### Data Analysis

The interviews were transcribed by a Health Insurance Portability and Accountability Act-compliant transcription company (Landmark Associates, Inc.), and any private health information was deidentified. The research team was trained in qualitative research methods and coded the transcripts in two cycles (9). In the first cycle, three team members independently coded five transcripts and then together developed a coding list. The coding list organized common ideas and phrases from the transcripts. In the second cycle, the transcripts and coding list were uploaded into NVivo software, and researchers applied codes to relevant quotations, amending the coding list if needed. Each transcript was double-coded. Coding differences were discussed by the three-member team and resolved by consensus.

The researchers conducted a content analysis of the codes to determine central themes. Team members independently used a focusing exercise to group the codes into clusters and described salient emotions, beliefs, and actions related to each coding cluster, as well as similarities and differences between adolescents and parents. Team

members then determined central themes with supporting quotations. Differences in the themes were discussed and resolved by consensus. Theme names and supportive quotations were considered by the broader multidisciplinary team and revised based on feedback. Finally, relevant quotations for each theme were placed in a series of tables limited to a single relevant quote per participant to evaluate the pervasiveness of themes among sampled adolescents and parents.

## Results

### Participant Characteristics

The research team conducted interviews with 22 adolescents and 25 parents, including 18 parent-child dyads. Adolescents were  $17.4 \pm 1.7$  years of age with a mean type 1 diabetes duration of  $9.7 \pm 4.0$  years; 68% were female, and 82% were non-Hispanic White (Table 1). Among the adolescents, 48% had dyslipidemia (mean LDL with hyperlipidemia  $161.4 \pm 33.7$  mg/dL). Parents were 41–60 years of age; 84% were mothers, and 88% were non-Hispanic White. Most parents (63%) held a college or graduate degree, and 72% worked full- or part-time.

### Themes

The study team identified five themes from the interviews. Themes related to adolescents' and parents' perceptions of complications and their preferences for learning about complications. Themes included "Limited Adolescent Knowledge of Complications," "Discussing Complications Is Important but Not Now or Not for Me," "Outside Sources Overestimate Risk," "Avoid Scare Tactics," and "Emphasize Prevention."

#### Limited Adolescent Knowledge of Complications

Adolescents demonstrated accurate but limited knowledge of diabetes LTCs, whereas parents demonstrated greater knowledge. When asked what they knew about complications, adolescents often responded with vague answers such as, "Not too much other than they're unhealthy" or "It's just really, really bad" (Table 2). Many adolescents specifically mentioned eye disease and extremities issues/amputations. Parents often mentioned kidney failure in addition to losing eyesight and amputations. Both adolescents and parents commonly described the organ itself (e.g., "eyes" or "kidneys") or organ failure (e.g., "blindness" or "leg amputation") rather than the early stages of organ involvement such as visual impairment, poor circulation, or neuropathy.

**TABLE 1** Characteristics of Participants

<i>Characteristics of adolescents (N = 22)</i>	
Age, years	17.4 ± 1.7
Duration of type 1 diabetes, years	9.7 ± 4.0
Male sex	32
Non-Hispanic White ethnicity/race	82
Education level	
Some university	32
Some high school	64
Some middle school	5
A1C, % (mmol/mol)	8.8 ± 1.2 (72 ± 12.5)
<i>Characteristics of parents (N = 25)</i>	
Age range, years	
41–50	54
51–60	46
Male sex	16
Non-Hispanic White ethnicity/race	88
Education level	
University or graduate degree	63
Some university or technical college	25
High school	13
Employment	
Full-time or part-time work	72
Nonworking by choice	16
Nonworking due to disability	12

Data are mean ± SD or %.

#### Discussing Complications Is Important but Not Now or Not for Me

Adolescents and parents of adolescents felt that providers should discuss complications with people with diabetes in general, but both groups expressed some reluctance to have the conversation themselves or at that particular time (Tables 2 and 3). Adolescents and parents described that LTCs should be discussed with people they perceived to be at higher risk of complications than themselves: older patients, patients with poor diabetes control, patients going off to college, or patients with diabetes for a longer time. Adolescents and parents also interpreted providers' limited emphasis of LTCs as a sign that the adolescent was not at risk. Some parents expressed that their adolescent already had too much to handle from the daily management of type 1 diabetes along with the challenges of adolescence and that discussion of LTCs would be "extremely overwhelming" or "a lot to handle." Other parents described that discussing current complications risks would not be helpful because present-day information was unlikely to apply to their child, who was years away from developing complications.

**TABLE 2** Themes and Quotes From Adolescents*Limited Adolescent Knowledge of Complications*

“Pretty much if you don’t take care of yourself, then you’ll get them [complications]. . . . You can probably lose limbs just because—I’m not quite sure. I mean, I know it’s happened, but I’m not really quite sure what the cause of it is, but I know that people will have to get stuff amputated or something because of it [diabetes].” —18-year-old male

“I haven’t really heard much—just that people can get very sick from the complications and that they [complications] can ultimately be very bad.” —16-year-old female

*Discussing Complications Is Important but Not Now or Not for Me*

“They’re [diabetes providers] not that worried about me in particular. . . . like I said, I haven’t heard about too much. That’s because I don’t have any of these issues, but I definitely think it should be heavily affected toward people who have these issues.” —15-year-old male

“I think as I get older, I’ll probably be more—I’ll look for it more because it’s gonna be more applicable to me and to my health and my life, but right now, I think I have all the information I need.” —19-year-old female

*Outside Sources Overestimate Risk*

“. . . because other family members also have diabetes, but they’re old-school diabetics, so they think you can’t eat this one thing, or else you’re gonna get sick, but you can. . . . I feel like they’re just exaggerating, and I feel like they’re kind of saying, ‘If you eat this one piece of cake, then you’re gonna end up in the hospital.’” —18-year-old female

“I hear about these bad things happening to people through the media, and television commercials . . . . I think a lot of it is media hype.” —18-year-old female

*Avoid Scare Tactics*

“I feel like [conversations with providers should be] not as a scare tactic but as a thing to be like, ‘Hey, if you don’t do this, this is what could and probably will happen.’” —18-year-old male

“Definitely what the complications actually could be and the effects of them and not just the scare tactic things, but the actual problems that could be in the future if things went wrong or don’t get better or something like that.” —16-year-old female

*Emphasize Prevention*

“If something came up that was concerning to them [diabetes providers], I would like to talk about how it could potentially affect me, or how it already is. Just so I know if there is something I could do to prevent something bad from happening.” —18-year-old female

“Yeah. Like if there’s anything interesting or something I should know, something that I should be on the lookout for or information to help me avoid something. That is always important. I would like to hear that.” —18-year-old male

**Outside Sources Overestimate Risk**

Participants described that their information on diabetes complications comes from many sources: media, friends, family, and health care providers. Although some adolescents and parents viewed the Internet as a relatively objective source, many expressed frustration that, in their views, nonmedical sources often overestimated risks and severity of LTCs. Many believed that information from television was “just exaggerating.” Some adolescents and parents were especially upset by television commercials.

Much of the perceived overestimation of complications risks was believed to derive from nonmedical sources confusing type 1 and type 2 diabetes. Some participants reported that friends and neighbors related stories of diabetes complications that affected their family members; for example, “how their grandfather lost a leg, or one of their toes was amputated.” Parents in particular expressed frustration that others confuse type 1 and type 2 diabetes. For example, a

mother commented that family members and school employees “don’t realize that type 1 diabetes in an adolescent is just not what they think. It’s not the same as type 2.”

**Avoid Scare Tactics**

Some parents and a few adolescents wanted providers to offer information on complications but without using scare tactics as a means of encouraging adolescents to take better care of themselves. Parents wanted the topic addressed “delicately” and acknowledged that “it’s a balance” to counsel adolescents on these topics by offering information rather than threatening poor future health. A few adolescents mentioned the importance of avoiding scare tactics, with a focus on avoiding over magnification and instead presenting a realistic depiction of “actual problems that could be in the future.”

**Emphasize Prevention**

Both adolescents and parents said they would like their clinicians to provide detailed information about specific

**TABLE 3** Themes and Quotes From Parents

*Limited Adolescent Knowledge of Complications (but Awareness in Parents)*

“I think normally the first thing that it can cause with the high blood sugar is either vision issues or neuropathy. It can cause heart attacks, strokes, numbness that makes it harder to have the ability to see [recognize] infections, amputations, and things like that.” —Mother of 15-year-old male

“... well, aside from heart attack and kidney failure and what else? Limbs, vision, kidney failure, heart attacks. I think the list goes on.” —Mother of 18-year-old female

*Discussing Complications Is Important but Not Now or Not for Me*

“His A1C is going down, things are looking better, so let’s not rock the boat. Let’s go with how things are—that he is improving, and we don’t need to focus on that negative stuff with him right now.” —Father of 18-year-old male

“... we’re focusing on all we can, which is trying to get compliance, but I do think that if you have a teen that is diabetes compliant and isn’t facing—doesn’t have challenges—then bringing up how do we avoid complications all together, I would be open to that. To be talking about those very long-term complications in the context of a kid who isn’t even gonna check their blood sugar, that would be—to me that’d be counterproductive because it would just be one more thing.” —Mother of 16-year-old female

“She’s doing such a good job and has pretty good physical health regardless of the diabetes, so I don’t know if I’d want to throw that on her right now. I really don’t think I would want to say, ‘Oh, by the way, [NAME]. You know if you get complications from diabetes, [it] could be X blah, blah, blah, blah.’ I think as she matures and gets older, if there’s problems, then she’ll be aware and be made to know about them. I don’t know if I want to put that on her head right now.” —Mother of 19-year-old female

*Outside Sources Overestimate Risk*

“Some of those commercials are horrible. . . . Not everybody’s gonna get every single ailment that goes along with that [diabetes], and every time these kids look at a TV they have to sit through those awful commercials . . . . You’ve got an 18-year-old that wants to jump through the TV set and strangle somebody.” —Mother of 18-year-old female

“A lot of times, you hear from people who they know somebody who has diabetes, and it’s an older person. They’re like, ‘Oh, so and so had diabetes, and, you know, this is what happened to them.’ You have to tell them if it’s type 2 or type 1 and all that.” —Mother of 16-year-old female

“I think television certainly takes things to the most drastic of all levels.” —Mother of 17-year-old female

*Avoid Scare Tactics*

“I don’t want her to be scared, but I want her to realize why control is important.” —Mother of 16-year-old female

“I’m not sure scare tactics really work . . . I think, trying to get him to remember that, again without scaring him too much, or making him feel bad, is important.” —Father of 18-year-old male

*Emphasize Prevention*

“Just how to prevent these issues, these health issues down the line. . . . I think the biggest thing is not so much what the complications are, it’s just how to avoid complications. What you can do to avoid complications, would be better than hearing all the things that could happen.” —Mother of 18-year-old male

“What predicts the risk factors [for complications] and how—what can be done to mitigate them . . . bringing up how do we avoid complications all together, I would be open to that.” —Mother of 16-year-old female

actions that can increase risks for LTCs and approaches to prevent such complications. Parents discussed wanting to get specific, personalized information such as “the percentage of risk” or “when something is going to happen” if poor glycemic control continues. In addition, rather than focusing on particular diabetes complications, adolescents and parents both wanted to know how complications could be prevented. They were most eager for conversations “focusing on how to avoid problems in the future.”

**Discussion**

In this qualitative study assessing adolescent and parent knowledge, opinions, and beliefs regarding diabetes LTCs, several themes emerged. Adolescents, more than parents, had

limited knowledge of diabetes complications. Adolescents and parents reported acquiring such knowledge from multiple sources in addition to their diabetes care providers, including news media, TV commercials, and friends, and often found these additional sources to be insensitive. Instead of threats or worst-case scenarios, adolescents and parents wanted their diabetes clinicians to provide hopeful, individualized messages about how LTCs could be avoided in the future. The timing of this education remains a complex issue, although both adolescents and parents felt that education about LTCs was better suited to older adolescents with a longer duration of diabetes.

Adolescents’ knowledge of complications frequently included blindness and amputations, two types of LTCs that are

particularly visible and emotionally fraught, resonating with the sensibilities of adolescent development, whereas parents identified a wider range of complications such as kidney or heart disease, which generally do not alter one's appearance. The study by Wysocki et al. (6), discussed previously, also described very limited complications knowledge in adolescents, with better but still limited complications knowledge in parents. Adults with type 2 diabetes have also shown a poor understanding of complications and of their risk of diabetes LTCs (10–13). Adolescents, and sometimes parents, often described organ failure (e.g., blindness) rather than earlier stages of organ involvement that are amenable to intervention and secondary prevention.

In other words, some adolescents and parents may not realize that early diabetic retinopathy need not necessarily indicate future blindness or that diabetic kidney disease may not indicate renal failure. Clinicians may want to emphasize that diabetes complications develop over years and that frequent follow-up visits (14), early identification (15), and early treatment (16–18) can prevent or delay the most severe forms of LTCs, even after an organ has begun to be affected.

Parents and adolescents endorsed obtaining information about diabetes LTCs from multiple sources, including the media. Similar to past work, we found participants frequently used sources such as the Internet and media, in addition to friends, family, and health care providers, to learn about LTCs (7). In our study, adolescents and parents found information from nonmedical sources to be exaggerated and believed such information pertained more to type 2 diabetes. As information of varying quality becomes increasingly accessible to families, clinicians become increasingly responsible for creating an open dialogue about the accuracy and relevance of these messages to adolescent patients and their families. Furthermore, clinicians can help inform adolescents and parents about reliable resources.

As shown in other studies, patients and families feel strongly that clinicians should emphasize the positive rather than use threats to motivate optimal self-care behaviors aimed at reducing risks of LTCs (7,19,20). This finding was further highlighted in a study eliciting guidance on provider conversations from adults commenting retrospectively on their experience growing up with type 1 diabetes, where “It’s going to be OK” and “Teach them, don’t scare them” emerged as major themes (21). Indeed, threats rarely serve as motivation to alter adolescent behaviors (22).

Adolescents and parents preferred that this information be presented in an individualized manner that emphasized hope for the future and possibilities for prevention. When counseling adolescents and parents, it may be helpful to first

gauge an adolescent's current level of knowledge about complications and the source from which their information was gleaned. Given that adolescents are exposed to emotionally charged, possibly inaccurate, information from TV commercials, other media, and friends or acquaintances, diabetes clinicians can play an important, supportive role in allowing adolescents to critically evaluate the information obtained from these sources and to counter this information with accurate, individualized, and age-appropriate messaging. Clinicians who may be inclined to avoid these conversations should realize that this avoidance can be misinterpreted by adolescents; adolescents may believe the absence of conversations about LTCs connotes an absence of risk for complications.

In our study, adolescents and parents demonstrated considerable ambivalence about discussing diabetes LTCs. They felt that such discussions were important hypothetically, but more apropos to others—often older people—and indicated that they did not want to engage in such conversations themselves. This observation is similar to the qualitative finding by Patino et al. (4) that adolescents perceived a greater risk of LTCs to others as opposed to themselves. Some parents felt that discussions at the current time would be particularly detrimental to the adolescent because of concurrent challenges. Previous studies have shown that discussion of diabetes LTCs at the time of diabetes diagnosis may be particularly difficult (1,23).

Thus, clinicians should be mindful of the timing of their conversations regarding complications education and tailor such discussions to adolescents' and parents' readiness. Adolescents and parents can offer input into the timing and desired depth of conversations about diabetes complications. Additionally, pediatric diabetes clinicians should realize that older adolescents and young adults transitioning to adult care will soon be confronting these complications, if not personally, then at least in discussions with their adult diabetes providers (23) or when they are sitting in a waiting room of an adult diabetes clinic (24,25).

During the pediatric care of adolescents with type 1 diabetes, the topic of complications can be addressed when adolescents are referred for routine eye examinations, and heart-healthy behaviors can be discussed during adolescence when high-risk behaviors such as smoking are discussed or at the time of routine lipid monitoring. Pediatric diabetes clinicians should consider discussing diabetes LTCs before their patients transition to adult care so that these patients are not overwhelmed with a new diabetes provider and new information about diabetes complications at the same time.

Our study has some potential limitations. First, the adolescents and parents were recruited from a single diabetes center,

and the majority were White and well educated, limiting the diversity of participants and generalizability of the study. On a related note, the majority of the parents in the study were mothers, so our results may not be generalizable to all parents and suggest the need for future research to assess the impressions of fathers on the topic of discussion of diabetes LTCs. Second, our adolescent participants were, on average, almost 18 years of age, making results possibly less generalizable to younger pediatric patients. Notably, there was variation in diabetes duration, providing some opportunity for application to a broader sample. Third, the study is potentially susceptible to selection bias because it was introduced to participants as being about LTCs; agreement or refusal to enroll might have been influenced by virtue of the topic. Those most worried about LTCs may have elected to enroll; others who become stressed by the topic of LTCs may have chosen to decline. Fourth, semistructured interviews may have influenced participant responses, leading them to say what they thought the interviewer wanted to hear; however, a non-clinician who was trained in appearing nonjudgmental performed the interviews, reducing the likelihood of engendering socially desirable responses. Finally, reproductive health and concerns around future pregnancy and the risk of diabetes in offspring represent other salient LTCs but were not covered in the study. Similarly, past studies of this age-group also did not include this topic (3,5,7), whereas there is a body of literature by Peterson-Burch et al. (26) on this important topic.

In summary, adolescents' knowledge of diabetes LTCs is limited, and much of that knowledge comes from outside sources, which may be inaccurate or exaggerate risk. Therefore, pediatric diabetes clinicians play an integral role in providing individualized, hopeful counseling regarding LTCs to adolescents and their families.

Larger studies encompassing a more diverse patient population could provide further information on the complex issue of timing of discussions about LTCs. Future research could focus on developing and testing interventions to train pediatric diabetes clinicians on best practices regarding the discussion of diabetes complications with adolescents and parents, as well as the timing of such discussions. In addition, future work could include developing a self-administered measure to assess knowledge of LTCs and related attitudes in adolescents with type 1 diabetes and their parents to more rigorously assess the outcomes of potential intervention studies.

**ACKNOWLEDGMENTS**

The authors thank the participants who generously shared their perspectives for this study.

**FUNDING**

This work was supported by grants from the National Heart, Lung, and Blood Institute (K23HL125976 [to M.L.K.]) and the National Institute of Diabetes and Digestive and Kidney Diseases (P30DK036836 [to the Joslin Diabetes Center] and 5K12DK094721-09), the Katherine Adler Astrove Youth Education Fund, the Maria Griffin Drury Pediatric Fund, and the Eleanor Chesterman Beatson Fund.

**DUALITY OF INTEREST**

M.L.K. is currently an employee of and stock shareholder in Eli Lilly. Her contribution to this work was completed during her employment at the Joslin Diabetes Center. No other potential conflicts of interest relevant to this article were reported.

**AUTHOR CONTRIBUTIONS**

M.L.K. and L.M.L. contributed to the study conception and design. The first draft of the manuscript was written by M.L.K., and subsequent drafts were revised by T.K., L.M.L., and M.L.K. Material preparation, data collection, and analysis were performed by all authors, and all authors read and approved the final manuscript. M.L.K. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**PRIOR PRESENTATION**

Material in this manuscript was presented at the Pediatric Endocrine Society's 10th International Meeting of Pediatric Endocrinology in Washington, D.C., 14–17 September 2017.

**REFERENCES**

- Lochrie AS, Wysocki T, Burnett J, Buckloh LM, Antal H. Youth and parent education about diabetes complications: health professional survey. *Pediatr Diabetes* 2009;10:59–66
- Katz ML, Guo Z, Laffel LM. Management of hypertension and high low-density lipoprotein in pediatric type 1 diabetes. *J Pediatr* 2018;197:140–146
- Jonker D, Deacon E, van Rensburg E, Segal D. Illness perception of adolescents with well-controlled type 1 diabetes mellitus. *Health Psychol Open* 2018;5:1–9
- Patino AM, Sanchez J, Eidson M, Delamater AM. Health beliefs and regimen adherence in minority adolescents with type 1 diabetes. *J Pediatr Psychol* 2005;30:503–512
- Castensøe-Seidenfaden P, Reventlov Husted G, Teilmann G, Hommel E, Olsen BS, Kensing F. Designing a self-management app for young people with type 1 diabetes: methodological challenges, experiences, and recommendations. *JMIR Mhealth Uhealth* 2017;5:e124
- Wysocki T, Lochrie A, Antal H, Buckloh LM. Youth and parent knowledge and communication about major complications of type 1 diabetes: associations with diabetes outcomes. *Diabetes Care* 2011;34:1701–1705
- Buckloh LM, Wysocki T, Antal H, Lochrie AS, Bejarano CM. Learning about long-term complications of pediatric type 1 diabetes: parents' preferences. *Child Health Care* 2016;45:399–413
- Katz ML, Guo Z, Cheema A, Laffel LM. Management of cardiovascular disease risk in teens with type 1 diabetes: perspectives of teens with and without dyslipidemia and parents. *Pediatr Diabetes* 2019;20:210–216
- Hashimov E. Qualitative data analysis: a methods sourcebook and the coding manual for qualitative researchers. *Technical Communication Quarterly* 2015;24:109–112
- Carroll C, Naylor E, Marsden P, Dornan T. How do people with type 2 diabetes perceive and respond to cardiovascular risk? *Diabet Med* 2003;20:355–360

11. Calvin D, Quinn L, Dancy B, et al. African Americans' perception of risk for diabetes complications. *Diabetes Educ* 2011;37:689–698
12. Martell-Claros N, Aranda P, González-Albarrán O, et al. Perception of health and understanding of cardiovascular risk among patients with recently diagnosed diabetes and/or metabolic syndrome. *Eur J Prev Cardiol* 2013;20:21–28
13. Rouyard T, Kent S, Baskerville R, Leal J, Gray A. Perceptions of risks for diabetes-related complications in type 2 diabetes populations: a systematic review. *Diabet Med* 2017;34:467–477
14. Jacobson AM, Hauser ST, Willett J, Wolfsdorf JI, Herman L. Consequences of irregular versus continuous medical follow-up in children and adolescents with insulin-dependent diabetes mellitus. *J Pediatr* 1997;131:727–733
15. James S, Gallagher R, Dunbabin J, Perry L. Prevalence of vascular complications and factors predictive of their development in young adults with type 1 diabetes: systematic literature review. *BMC Res Notes* 2014;7:593
16. Mauer M, Zinman B, Gardiner R, et al. Renal and retinal effects of enalapril and losartan in type 1 diabetes. *N Engl J Med* 2009; 361:40–51
17. Remuzzi G, Ruggenti P, Perico N. Chronic renal diseases: renoprotective benefits of renin-angiotensin system inhibition. *Ann Intern Med* 2002;136:604–615
18. Parving HH, Hommel E, Jensen BR, Hansen HP. Long-term beneficial effect of ACE inhibition on diabetic nephropathy in normotensive type 1 diabetic patients. *Kidney Int* 2001;60:228–234
19. Buckloh LM, Lochrie AS, Antal H, et al. Diabetes complications in youth: qualitative analysis of parents' perspectives of family learning and knowledge. *Diabetes Care* 2008;31:1516–1520
20. Ritholz MD, MacNeil T, Weinger K. Difficult conversations: adults with diabetes and the discussion of microvascular complications. *Diabet Med* 2017;34:1447–1455
21. Freeborn D, Dyches T, Roper SO. Lessons learned from a life with type 1 diabetes: adult perspectives. *Diabetes Spectr* 2017;30:188–194
22. Bond GG, Aiken LS, Somerville SC. The health belief model and adolescents with insulin-dependent diabetes mellitus. *Health Psychol* 1992;11:190–198
23. Visentin K, Koch T, Kralik D. Adolescents with type 1 diabetes: transition between diabetes services. *J Clin Nurs* 2006;15: 761–769
24. Garvey KC, Beste MG, Luff D, Atakov-Castillo A, Wolpert HA, Ritholz MD. Experiences of health care transition voiced by young adults with type 1 diabetes: a qualitative study. *Adolesc Health Med Ther* 2014;5:191–198
25. Dovey-Pearce G, Hurrell R, May C, Walker C, Doherty Y. Young adults' (16–25 years) suggestions for providing developmentally appropriate diabetes services: a qualitative study. *Health Soc Care Community* 2005;13:409–419
26. Peterson-Burch F, Abujaradeh H, Charache N, Fischl A, Charron-Prochownik D. Preconception counseling for adolescents and young adults with diabetes: a literature review of the past 10 years. *Curr Diab Rep* 2018;18:11