

Lessons Learned From a Life With Type 1 Diabetes: Adult Perspectives

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ABSTRACT

Adults who have lived much of their life with type 1 diabetes have learned lessons that can benefit health care providers (HCPs), families, and young people who live with the condition. This study was undertaken to gain a better understanding of the challenges of growing up and living with type 1 diabetes from adults who have experienced those challenges and to recommend strategies for parents, caregivers, and HCPs who work with children or adolescents with type 1 diabetes. Thirty-five adults with type 1 diabetes participated in this qualitative study consisting of two in-depth interviews with each participant. Six themes emerged: 1) It's not who you are. 2) Don't let it limit you. 3) Get involved in diabetes support groups. 4) It's going to be OK. 5) Teach them; don't scare them. 6) Don't single kids out. Through hindsight and the more mature perspective of adulthood, study participants were able to share valuable insights that could inform the efforts of those who work with or care for younger people with type 1 diabetes.

Type 1 diabetes, a chronic disease that is usually diagnosed in childhood, lasts a lifetime. Although it is most commonly diagnosed within a bimodal distribution peaking at ages 2–6 and again at 10–14 years of age (1), it can be diagnosed at any age. Recent studies suggest its incidence is rising. Research has shown a 3% annual increase in cases of type 1 diabetes in the United States, with ~1 in every 400 children diagnosed (>13,000 annually) (2–4). In Europe, the increase in cases of type 1 diabetes is 3.9% per year for all age-groups, prompting the prediction of a significant increase in the number of cases by 2020 (5,6). In addition, the increasing mortality due to type 1 diabetes in areas such as sub-Saharan Africa, where it used to be extremely rare, underscores the worldwide significance of the disease (7).

Type 1 diabetes is an autoimmune disease that destroys insulin-producing

cells of the pancreas, thus causing hyperglycemia when uncontrolled and hypoglycemia due to insulin administration or excess exercise. Both hypo- and hyperglycemia can lead to serious short- and long-term complications. Short-term complications such as weakness, confusion, seizures, ketoacidosis, and diuresis must be identified quickly and treated with either insulin or glucose administration, depending on the source of the symptoms (8,9). Long-term complications affect both micro- and macrovascular systems, leading to retinopathy and blindness, renal disease, cardiovascular disease, immune suppression, neuropathy, autonomic nervous system dysfunction, and peripheral arterial disease (9,10).

Properly managing glycemia by monitoring carbohydrate intake and blood glucose levels and administering insulin numerous times throughout the day (4) can prevent

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<https://doi.org/10.2337/ds16-0032>

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or minimize long-term complications associated with the heart, eye, and kidney (4). However, such management is challenging for children and adolescents with type 1 diabetes and their families, and success is related to family social support, parental supervision, and beliefs about a diabetes cure (11–13). Although children and adolescents exhibit knowledge about diabetes and its consequences (14), those believing adherence to their treatment regimen will not make a difference (11) or that there will be a cure (13) demonstrate low levels of adherence and higher A1C levels.

Children and adolescents with type 1 diabetes identify low blood glucose, dietary restrictions, insulin injections, and feelings of being different as stressors and challenges (15–18). Because such challenges can affect their adherence to their diabetes management regimen and their quality of life (19), it is important to learn appropriate strategies to assist them in coping with these challenges, adjusting to their situation, improving their quality of life, and encouraging more understanding and appropriate relationships within the family.

Adults with type 1 diabetes, who have faced the challenges of growing up and living with the condition, can provide a mature perspective not yet available to children and adolescents. However, little research has focused on these adults, except to investigate the challenges that arise during the transition from adolescence to young adulthood (16,20–23). Adult perspectives of growing up and living with type 1 diabetes can provide a greater understanding of childhood challenges, insights into what did and did not work for them, and suggestions regarding appropriate interventions for young people with the disease. The purposes of this study were 1) to gain a better understanding of the challenges of growing up and living with type 1 diabetes from adults who have experienced those challenges and can look back on them with

adult perspectives and knowledge and 2) to recommend strategies or interventions for parents, caregivers, and health care providers (HCPs) who work with children and adolescents with type 1 diabetes.

Design and Methods

A sample of 23 women and 12 men ranging in age from 19 to 70 years (mean 36.54, SD 16.65) were enrolled after obtaining university and hospital institutional review board approvals. Age at diagnosis ranged from 2 to 35 years (mean 15.06, SD 9.84), and time since diagnosis ranged from 1 to 54 years (mean 21.46, SD 12.87). Participants volunteered in response to a flyer distributed by a diabetes clinic or word of mouth. Inclusion criteria included diagnosis of type 1 diabetes and age ≥ 18 years. Interviews took place in locations convenient to participants or, if preferable to the participant, by phone.

This qualitative study, using the biographical method, consisted of two in-depth interviews. Two interviewers were present for each interview. On average, the interviews lasted 1 hour (range 45–90 minutes). The first interview allowed the participant to answer the prompt “Tell me about growing up and living with type 1 diabetes.” The interviewers used additional prompts such as “Tell me more about . . .” or “Can you explain that further,” but the participant directed the interview. The second interview took place approximately 1 week later. At this session, the interviewers began by soliciting any necessary clarification from the first interview. The interviewers then asked the following questions: 1) Tell us about when you were diagnosed with type 1 diabetes. 2) What challenges do you remember? 3) How did your challenges change over time? 4) Tell us about how you self-manage your diabetes. 5) Tell us about interactions with your parents and family. 6) What would you share with parents of children/adolescents with diabetes? 7) What would you

share with children/adolescents with diabetes?

Interviews were transcribed verbatim, entered into NVivo version 9 software (QSR International, Melbourne, Australia) and coded independently, and verified by two or three researchers. The initial coding was performed by a researcher with a doctorate in nursing. Coding was verified by a second researcher with a doctorate in specialized educational development. When questions about coding arose, a third researcher with a doctorate in family and child development provided additional verification.

The transcripts were analyzed line by line for codes that revealed major and minor themes, following guidelines established by Denzin and Lincoln (24). Themes and subthemes were discussed until consensus was reached among the entire research team. Repetition of themes was noted both within and across interviews (25). Exemplars then were chosen. Trustworthiness, as demonstrated by objectivity of data, was established by having another investigator read the transcripts and confirm initial findings and through researcher and peer debriefings with two individuals with type 1 diabetes to establish an audit trail and provide triangulation of data (24).

Results

Six major themes emerged related to experiences of living with type 1 diabetes: 1) It's not who you are. 2) Don't let it limit you. 3) Get diabetes support. 4) It's going to be OK. 5) Teach them, don't scare them. 6) Don't single kids out.

It's Not Who You Are

All nine participants who were diagnosed between the ages of 2 and 10 years emphasized that type 1 diabetes does not define who a person is. In addition, other participants, including one diagnosed between the ages of 11 and 19 years and two diagnosed after the age of 20 years, commented that diabetes was only a part

of their lives—not their entire life. Participants who had lived most of their lives with type 1 diabetes wanted everyone to know that diabetes did not dictate their lives. As one 54-year-old woman who was diagnosed at age 10 stated, “I am a person with diabetes. I am not a diabetic. It does not dictate who I am or what I am. It is just part of my life.”

No participants suggested that having type 1 diabetes was easy or did not change their life. However, they emphasized that the disease did not make them different from other people, and most (55%) described how taking care of themselves kept them from being different. A 23-year-old woman who was diagnosed at age 2 explained:

You don't have to let this take over your whole life. As long as you know what to expect or know the best way to deal with it, you can totally lead a normal life. Just kind of do what you want to do, as long as you're a little more cautious and smart. Listen to your body.

A 24-year-old man who was diagnosed at age 4 gave a different perspective on how taking care of oneself keeps one from being different:

If you're on top of it, it doesn't take very long, and you aren't different. You become increasingly more different than your peers when you're not taking care of it. If I was always completely on top of my diabetes in high school, my blood sugar would be just like all my teammates. If you're in control of it, there's no reason it has to differentiate you from others, but if you're out of control, then you're completely different from other people.

Don't Let It Limit You

Not allowing type 1 diabetes to limit their activities was important to par-

ticipants whether they were diagnosed at a young age, in adolescence, or as adults. However, how they learned that the disease did not have to be limiting was different for those in each age-group. Those diagnosed at a young age credited their parents with instilling the attitude that they could do whatever they wanted. For example, a 24-year-old man who was diagnosed at age 4 stated, “The thing I respect most about how my parents raised me—they taught me that diabetes is not a problem. There's no reason you can't do anything because of your diabetes.”

Many participants who were diagnosed as adolescents initially struggled with the misunderstanding that there would be limits placed on them. However, over time, they changed their attitudes. For example, a 38-year-old man who was diagnosed at age 19 initially believed that type 1 diabetes would negatively affect his life. He said, “In my mind, it would affect everything I thought I could do.” Another participant, a 25-year-old man who was diagnosed at age 19, also initially thought his life would be limited, but later changed his mind. He stated, “Your life isn't over. You can still do everything you want to do.”

Most participants who were diagnosed as adults emphasized that having a positive attitude and being careful allowed them to do anything they wanted. For example, a 63-year-old woman who was diagnosed at age 23 said, “Because I was determined that I was going to make the best of it, and it wasn't going to stop me from doing anything I wanted to do, I just had a positive attitude that I was still going to live a good life.” Another participant, a 67-year-old man diagnosed at age 35, was determined to not allow type 1 diabetes to limit his activities—especially scuba diving. Instead, he learned what measures he would need to take to safely engage in scuba diving. As he said, “Well, I haven't been limited. I like to scuba dive, and so when I scuba dive, I have

to be real careful. I've done a lot of research on diabetic scuba diving, but I'm real careful.”

Get Diabetes Support

Seeking support and learning from others with type 1 diabetes was important to many participants. Support groups for children included diabetes camps. One participant, a 23-year-old woman diagnosed at age 2, described how going to camp helped her feel that she fit in:

I went to [diabetes] camps for 3 years, and it was the best time of my life. Because . . . suddenly you're put in this situation with a hundred other kids that are suddenly just like you. And you all stop and check your blood sugar at the same time, and you all stop and have the same meals and sit down and count carbohydrates together and work with the nurse to figure out how much insulin you need. And it wasn't just you, so it was that kind of “I fit in” type of feeling.

For participants diagnosed as adolescents or adults, knowing someone else with type 1 diabetes was important. One participant, a 31-year-old woman diagnosed at age 12, explained how important having a friend with type 1 diabetes has been for her:

So now I have a really good friend who has type 1. We've been pregnant together. We're able to call each other. We're both on insulin pumps. We both just know. But we're able to call each other all the time. That's nice.

It's Going to Be OK

Although being diagnosed with type 1 diabetes changes many aspects of a person's life, all participants emphasized that everything was going to be OK. It did not matter whether a participant was diagnosed as a child,

adolescent, or adult; each one learned that it was going to be OK. One participant, a 31-year-old man diagnosed at age 4, offered this advice: "It's OK to be mad; it's OK to be sad; it's OK to cry. But despite all that, they are going to be OK. And it's OK to express that emotion and share all that and be frustrated, but they are going to be OK."

Another participant, a 30-year-old woman diagnosed at age 9, agreed that it was OK not to like diabetes; in fact, it was OK to hate it:

I think that diabetes is hard. Let kids know that it's OK to hate it. It's OK to not like it. It's OK to wish you didn't have it and wish that it would go away. You don't have to pretend to be happy and minimize it. You know . . . at least it's not cancer, at least it's not AIDS, at least it's not this or that. At the same time, your life is not over. Try and look at it realistically. I think often-times you see your diabetes as this huge problem, and it's all you focus on, and it's all you're gonna see. Kind of the idea of the beam. If you have it up in front of your eye super close and it's all you focus on, you can't see everything in your life. So maybe diabetes . . . you don't like it. That doesn't have to mean your whole life stinks, so just learn to accept it as part of life, and that it can be OK.

A 23-year-old woman diagnosed at age 17 explained how the passage of time helped her understand that it was going to be OK: "It's a lot, and you're not going to believe it, but you're going to look back 6 months from now and realize that life did go on, and you're OK. Things really are alright." Another participant, a 45-year-old man diagnosed at age 31, identified how using a pump helped to make everything OK for him:

"Since I got the pump, you don't have to worry about it as much. You always have it with you. It becomes just so much a part of my every day. I don't hardly think about it much."

Teach Them, Don't Scare Them

Participants who were adolescents or preadolescents at the time of diagnosis described differences in the ways HCPs talked to them about the importance of diabetes management for long-term health outcomes and offered recommendations for HCPs. Some were concerned that HCPs used scare techniques to motivate them to manage their blood glucose better, whereas others felt that HCPs avoided teaching them about long-term consequences because they were worried about scaring them. One participant, a 28-year-old woman diagnosed at age 12, attended diabetes camp only once because of the negative experience she had:

. . . the people who were there, who were teaching us . . . I felt like they were using scare tactics. . . . it wasn't like, "You can do this, and it's going to be great, and you know people are diabetic. . . . If you don't do it, you can have a really hard life, but you can do it!" It totally was not like that. It was like, "Look, this could kill you."

Another participant, a 31-year-old man diagnosed at age 16, believed that it was important that those with type 1 diabetes be taught about the potential long-term consequences of the disease. However, he felt that it had to be done in a way that was not depressing or discouraging. He stated:

Certainly it's depressing if someone is saying you could have kidney failure, you could have all these other things. I think that however you ended up packaging it would be the key. I think it's still important, though, to educate them on the

long-term effects of not taking care of yourself. It's probably just a matter of how you deliver it. But, certainly, if it was delivered in a wrong way, it could be very discouraging.

Other participants also addressed the importance of teaching children and adolescents about the potential long-term consequences. One participant, a 31-year-old woman diagnosed at age 12, believed that she had not been taught about consequences because no one wanted to scare her. When her A1C reached high levels, her nurse sat down and talked with her:

She just told me, like, the facts: this is what can happen to people if they don't take care of themselves. And she told me all the long-term consequences that can happen that no one really told me before. And probably because they don't want to scare 12-year-olds, but by that time, I think I was 14 and, you know, . . . I'm sure she just wanted to take care of me. And the only way to do that is you [have to] take care of yourself.

Don't Single Kids Out

Participants of all ages stressed that having diabetes did not make them different. Some participants, however, were made to feel different by being singled out. As a 28-year-old woman diagnosed at age 12 explained:

I just didn't want to be singled out. I remember when I was a sophomore in high school and I went to my geography class and I had low blood sugar in the class, so I got out a juice box, and I drank my juice box, and I put it away. The teacher called me out and said, "There is no food or drink allowed in class, and you need to go throw it away

right now.” I felt so embarrassed for being singled out.

Another participant, a 19-year-old woman diagnosed at age 7, explained how important it is to let kids be kids, stating:

Don't go around your neighborhood on Halloween and give them healthy stuff to give to your kids. That's just weird. I knew people that did that to their kids, and I mean, that's fine, 'cuz they want to be healthy, and they don't want their blood sugars to be crazy. But you still have to live; you still have to be a kid.

Participants noted that families can help their family member with diabetes be healthier without making them feel different. A 21-year-old woman diagnosed at age 16 explained:

My parents started running and started eating healthier. So we kids started as well. I think that helps a lot because I saw my parents eating healthier, and that's what was in the cabinets too—healthier foods. So that's what I would eat. Get the whole family to do it, 'cuz you're supposed to be doing it anyway. I think you don't have to single out your diabetic child and be like, “Hey, you need to eat healthier,” when you're munching on a Little Debbie or something.

Discussion and Clinical Implications

The purpose of this study was to gain an understanding of the experiences of growing up with type 1 diabetes from the perspective of adults diagnosed with the disorder. This study included 35 adults who had widely varying durations of diabetes (diagnosed 1–54 years before the study; mean duration 22.13 years). With a wealth of experience and the maturity that comes with age, participants

provided a unique perspective on the experience of growing up and living with type 1 diabetes. Learning from adults who have lived for many years with type 1 diabetes can help HCPs and the parents and caregivers of children and adolescents evaluate and improve their own health promotion and diabetes management strategies.

Participants repeatedly emphasized that type 1 diabetes is “not who you are.” This is an important message for children and adolescents with type 1 diabetes, who often identify feeling different as a major challenge of living with the disease (26). Feeling defined by their diabetes may contribute to feeling different from others, which can result in refusing to participate in diabetes management when with peers (27). Parents and HCPs can help children and adolescents understand that good diabetes management can prevent the health challenges that make them different from their peers. As stated by participants, “you aren't different” but “if you're out of control, then you're completely different from other people.”

Participants also emphasized that type 1 diabetes did not limit their activities and that having a positive attitude about their abilities allowed them to continue their favorite activities; as they stated, a person with type 1 diabetes can “do everything you want to do.” Although the American Diabetes Association (28) emphasizes that individuals with type 1 diabetes can participate in normal activities and strive to achieve their goals, participants mentioned that, as children and adolescents, they worried that they would not be able to do the things they had planned to do with their lives. Participants emphasized that it is important for children and adolescents to understand that they do not need to limit their activities. In fact, studies have shown that physical activity and participation in organized sports have positive health benefits for children and adolescents with type 1 diabetes (29,30). Parents

and HCPs should promote an honest discussion with their child/patients about their future goals and how they can accomplish those goals despite having type 1 diabetes. This can promote a more positive attitude and help children and adolescents understand how maintaining good diabetes management allows them to participate in their desired activities.

Participants stressed the importance of associating with other people who have type 1 diabetes such as at a diabetes camp. These associations and friendships helped participants feel that they fit in and that they had someone they could talk with about the challenges of living with diabetes. Although many studies have explored the health benefits of diabetes camps for children and adolescents with type 1 diabetes, few have reported on their psychosocial benefits as discussed in this study, with adults reflecting on their experiences. Kimmelblatt (31), however, found that children attending diabetes camp demonstrated a decrease in depression and anxiety, an increase in self-concept, and an improved attitude about having type 1 diabetes. Parents and HCPs should encourage their children/patients to participate in diabetes camps, support groups, or other activities that allow them to interact with other people their age who have type 1 diabetes.

Most participants wanted children and adolescents with diabetes to understand that everything was going to be OK. They acknowledged that, at their diagnosis, the prospect of living with type 1 diabetes was overwhelming, and most of them believed that their life as they knew it was over and that nothing would ever be the same. The participants wanted young people to know that it was OK to be angry and upset, but that they could do what they wanted to do with few limitations. Although quality of life is a frequent focus of type 1 diabetes research (32–34), no studies have addressed the importance of children and adolescents with type 1 diabetes learning that they can still do the

things they had previously planned on doing in life. Participants emphasized how important it is for parents and HCPs to demonstrate a positive attitude about type 1 diabetes and avoid comments that may validate young people's belief that the life they knew is over because of their diagnosis.

Participants addressed the challenge of educating young people about type 1 diabetes without using fear tactics focused on devastating complications or, the other extreme, of failing to educate them adequately to avoid scaring them about potential complications. Neither approach was acceptable to participants, who emphasized the importance of teaching young people about type 1 diabetes in a respectful, factual manner, but without drama or predictions of future catastrophes. Although studies have examined the effectiveness of diabetes education programs for patients with type 1 diabetes, their focus has been on achieving improved glycemic control (35,36), not on patients' perceptions of the teaching techniques. Parents and HCPs should be aware of the negative effect that scare tactics may have on children or adolescents with type 1 diabetes. Teaching these young people about the importance of diabetes management should be done in a matter-of-fact manner, without dwelling on potential complications, just as teaching a young person the importance of using a seat belt while driving or wearing a helmet while riding a bike does not necessitate vivid descriptions of potential life-threatening injuries.

Finally, participants stressed the importance of families and teachers not treating young people with type 1 diabetes differently from other children. Participants shared their experiences of being treated differently and other experiences when they were treated similarly to other classmates or family members. For children and adolescents with type 1 diabetes who are struggling to feel

normal, being treated normally is important. This is consistent with studies reporting the benefits of not treating children or adolescents differently from their peers (37,38). HCPs should address this issue with parents, not only at the time of their child's diagnosis, but also as the child or adolescent grows and develops. HCPs should remind parents of the importance of having age-appropriate expectations and not focusing on only diabetes management requirements, but rather on the child as a whole person.

Conclusion

Participants ranged in age from 19 to 70 years and had had type 1 diabetes for 1–54 years. For some, their diabetes experiences began before the advent of home blood glucose testing and insulin pumps. However, as adults, they had the ability to look back over their experiences and understand what worked for them and what did not, and they were able to share many insights. The lessons they learned from living to adulthood with type 1 diabetes can be valuable to parents and HCPs. In addition to heeding these lessons, however, parents and HCPs should give the children and adolescents they care for the opportunity to talk about their own experiences and what is and is not working for them. Care can then be personalized to better meet both their physical and their psychosocial needs.

Duality of Interest

No potential conflicts of interest relevant to this article were reported.

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