



Focus on the Positive: A Qualitative Study of Positive Experiences Living With Type 1 or Type 2 Diabetes

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The purpose of this study was to identify positive experiences associated with diabetes from the perspective of adults diagnosed with type 1 or type 2 diabetes. We conducted in-depth face-to-face and telephone interviews with adults with diabetes. Participants focused on positive and supportive experiences with their peers and community, improved health behaviors, personal growth, and engagement in diabetes advocacy. Communicating positive experiences about diabetes may help clinicians and educators reframe the negative messages commonly shared with people with diabetes.

Diabetes is one of the most significant health problems in the United States and globally. In the United States, an estimated 34.2 million people of all ages—or 10.5% of the population—have diabetes, with the vast majority having type 2 diabetes (1). Diabetes is a group of diseases characterized by high blood glucose levels resulting from the body's inability to produce or use insulin (2). The two most common forms are type 1 diabetes and type 2 diabetes (2); the former is marked by the body's inability to produce insulin and the latter by the body's inability to make enough insulin or to effectively use the insulin it produces (2). Although type 1 diabetes is most commonly diagnosed in childhood or adolescence, it can occur at any age. Likewise, type 2 diabetes is most commonly diagnosed during middle age but can be diagnosed in childhood or adolescence. Recent trends in incidence show increases in both type 1 and type 2 diabetes, especially in children and adolescents (1).

Recent data from the Centers for Disease Control and Prevention show that half of U.S. adults with diagnosed diabetes (50.0%) have an A1C value at target (<7.0%) (1). Of these, 19.2% were both nonsmokers and met all three "ABC goals": A1C <7.0%, blood pressure <140/90 mmHg, and non-HDL cholesterol <130 mg/dL (1). Reaching ABC

goals decreases the risk of macrovascular (e.g., cardiovascular disease) and microvascular (e.g., retinopathy, neuropathy, and nephropathy) complications (3–5). Behaviors that promote ABC goal achievement, and in turn reduce the risk for complications, include smoking cessation (6), following a healthy diet (7), losing weight (8), engaging in regular physical activity (9), monitoring blood glucose levels (10), taking medication (11), checking feet (12), and attending clinic appointments (13,14). Active engagement in these behaviors is encouraged in diabetes self-management education and support (DSMES) programs (15,16).

DSMES is an important component of care for all people with diabetes (16). DSMES should be person-centered and facilitate learning about diabetes, participating in diabetes decision-making, and acquiring skills for self-care (16). Furthermore, providers who deliver DSMES should incorporate positive, strengths-based language to reduce stigma and feelings of shame and guilt (17,18). Historically, diabetes care and DSMES have focused on behavioral and clinical targets, which may explain their short-term benefits but limited long-term effects on outcomes (19,20). Incorporating personal stories and experiences into diabetes management may help adults with diabetes sustain the benefits they accrue (21–23). However, minimal research has explored positive stories and experiences of living with type 1 or type 2 diabetes. Thus, the purpose of this study was to identify positive experiences with diabetes from the perspective of adults diagnosed with either of these forms of the disease.

Research Design and Methods

Research Design

Focused ethnographic methods were used in this study to describe the positive experiences of living with type 1 or

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type 2 diabetes. Focused ethnography is a means of accessing experiences, perspectives, and behaviors in the context in which they occur, thereby improving our understanding of factors surrounding health and disease (24). As in other forms of qualitative research, the data collected are rich in their descriptions of what people know, believe, and do. In focused ethnography, informants or participants may not be connected by the same culture in the broadest sense; however, they typically share behavioral norms, local knowledge, and a common language from living through a common experience (e.g., living with type 1 or type 2 diabetes). For the purposes of this study, the diagnosis of type 1 or type 2 diabetes was the sociocultural context of the participants. Participants shared their diagnosis, diabetes education practices (e.g., checking feet daily), diabetes beliefs (e.g., hyperglycemia is serious), diabetes language (e.g., diabetes terminology such as insulin pumps, diabetic ketoacidosis, and neuropathy), and recommended self-care behaviors (e.g., blood glucose monitoring and taking medications). We chose to include participants with either type 1 or type 2 diabetes given the shared experiences, diabetes education practices, diabetes beliefs, diabetes language, and recommended self-care of the two groups.

The University Office of Research Compliance approved the protocol and all recruitment procedures and materials (18-X-346). All participants provided informed written or verbal consent before participation.

Sample

We used maximum variation sampling (25), a form of purposive sampling, to recruit adults ≥ 18 years of age who were able to read and speak English and were diagnosed with either type 1 or type 2 diabetes. Exclusion criteria included individuals whose diabetes diagnosis could not be clearly identified as one of these forms, those with maturity-onset diabetes in the young, those < 18 years of age.

Participants were recruited via flyers, e-mail messages, University-owned and maintained listservs, and word of mouth. Individuals interested in participating contacted a study investigator (M.A.C. or E.A.B.) via e-mail or phone and left their information to be contacted. Individuals who met all inclusion and exclusion criteria were included in the study. Participants were explicitly informed that there were no right or wrong responses to the interview questions and that they could decline to participate at any time without explanation. Participants received a \$10 gift card or cash as compensation.

Data Collection

We designed a semistructured interview guide and field-tested it with two participants (Table 1). Two trained interviewers (M.A.C. and E.A.B.) conducted all interviews, asking participants broad, open-ended questions about diabetes self-care, health care experiences, social networks, career aspirations, community involvement, and messages for newly diagnosed individuals with diabetes.

Sixteen interviews were conducted in person in conference rooms and university offices. Four interviews were conducted via telephone because of the coronavirus 2019 pandemic. Interviews lasted 20–60 minutes. We collected data until saturation was reached, that is, until no new information was generated from the interviews (25).

Interviews were digitally audio-recorded and transcribed verbatim. We performed quality checks of the transcribed files while listening to the recordings to validate the transcriptions. Names and identifiers were removed to protect participant confidentiality.

Qualitative Analysis

The multidisciplinary research team, consisting of a health behaviorist/qualitative methodologist (E.A.B.) and an exercise physiologist (M.A.C.), analyzed data using content and thematic analyses (26). Specifically, we performed content analysis by independently marking and categorizing key words, phrases, and texts to identify themes (27). We met to code the data and reviewed, discussed, and resolved all discrepancies via consensus to establish intercoder reliability (27). The Cohen's κ coefficient between the two coders was 0.918, indicating very good agreement (28). No negative or deviant cases were excluded from the analysis (29).

After the transcripts were coded and reviewed, one member of the research team (M.A.C.) entered the coded transcripts in NVivo 12 software (QSR International, Victoria, Australia) to organize the coded data. We selected themes that characterized participants' positive experiences that occurred multiple times, both within and across transcripts.

Rigor

To support credibility (validity), we triangulated the investigators with expertise from different disciplines, including health behavior, qualitative methodology, and exercise physiology. Analyst triangulation provided a check on selective perceptions, as well as a means of identifying blind spots in the analysis (30). Further, three

TABLE 1 Interview Guide

Questions

1. Can you please share any positive experiences you have as a result of living with diabetes?
2. Have you experienced anything positive with your health behaviors?
3. Have you experienced anything positive with your social network?
4. Have you experienced anything positive with your personal growth?
5. Have you experienced anything positive with your career aspirations?
6. Have you experienced anything positive in your community?
 Probe: in your diabetes community?
 Probe: in your home community?
7. Can you foresee any positives in the future with your diabetes?
8. Are there any positive messages you would like to share with newly diagnosed individuals with diabetes?

participants reviewed the findings to achieve participant corroboration (31). We supported transferability (external validity) via rich descriptions and verbatim quotations from the transcripts. To support dependability (reliability), a researcher not involved with the study conducted an external audit to examine the research process and confirm that the findings were supported by the data (29). Finally, we supported confirmability (objectivity) through tracking the decision-making process with an audit trail, which is a detailed description of the research steps conducted from the development of the project to the presentation of findings (30).

Results

Twenty adults (age 41.5 ± 19.3 years, A1C $7.3 \pm 1.7\%$, diabetes duration 12.9 ± 10.3 years, BMI 29.2 ± 8.6 kg/m², 65.5% prescribed insulin injections, 50.0% female, 100% White [Table 2]) participated in the study. Transcript identifiers are used with quotations indicating participant number, type of diabetes (T1D or T2D for type 1 or type 2 diabetes, respectively), and duration. The following themes emerged from the data analysis.

Positive and Supportive Community

All participants described positive experiences with their support system and community (100%, $n = 20$). Many expressed gratitude for people who checked in on them during episodes of hyperglycemia and hypoglycemia. They valued the support and sense of community they received from different sources, including their families, friends, roommates, classmates or coworkers, and the online diabetes community. As one participant described,

“The other thing that has been a really positive experience for me is just the way that my family has rallied behind me and really taken ownership of my health. I think that that means a lot, and I’m grateful for that every day.” (ID 117, T2D, 1-year duration) Another participant shared appreciation for roommates’ involvement in care and willingness to learn about diabetes: “Also, I’ve made my friends and my roommates more aware because I genuinely don’t think [they] would know really what diabetes was if I didn’t have it . . . Educating my friends about it has definitely been a positive outcome.” (ID 101, T1D, 10-year duration) Additionally, some participants spoke about the formation of new friendships because of diabetes: “I’ve had some kind of friendly interactions with other people with diabetes, especially people who wear pumps . . . I would say that diabetes is a means of connection that allowed us to introduce each other.” (ID 108, T1D, 42-year duration)

Participants also talked about the unique support they received from the online diabetes community. The online diabetes community consists of thousands of people with diabetes sharing information, advice, and encouragement to each other across many different platforms, including social media.

“I find the whole diabetes community like a family. Everyone is willing to help each other out . . . Something a little small, but whenever I like have something or even if it’s not diabetes-related, half of my [online] comments are people from the diabetes community saying, ‘Oh, this is great!’ ‘Yeah, we love you.’ ‘Miss you,’ or something like that. So, it’s a very tight-knit group.” (ID 100, T1D, 9-year duration)

TABLE 2 Demographic and Health Characteristics of Participants ($n = 20$)

	Value	Range
A1C, %	7.3 \pm 1.7	5.4-13.0
BMI, kg/m ²	29.2 \pm 8.6	21.1-59.7
Age, years	41.5 \pm 19.3	19-72
Diabetes duration, years	12.9 \pm 10.3	1-42
Type of diabetes		
Type 1	12 (60.0)	
Type 2	8 (40.0)	
Education		
Current undergraduate student	6 (30.0)	
Two-year college degree	1 (5.0)	
Four-year college degree	3 (15.0)	
Current graduate or professional student	2 (10.0)	
Some graduate work	1 (5.0)	
Completed master's or professional degree	3 (15.0)	
Advanced graduate work or doctorate	4 (20.0)	
Prescribed diabetes medications		
No medication, managed by diet and exercise	1 (5.0)	
Oral diabetes medication(s)	6 (30.0)	
Insulin	13 (65.0)	
Insurance coverage		
Private insurance	17 (85.0)	
Medicaid/Medicare	3 (15.0)	
Sex		
Female	10 (50.0)	
Male	10 (50.0)	
White race	20 (100.0)	
Relationship status		
Single/never married	11 (55.0)	
Married	8 (40.0)	
Divorced	1 (5.0)	
Occupational status		
Working full-time	7 (35.0)	
Working part-time	1 (5.0)	
Student	8 (40.0)	
Retired	4 (20.0)	
Income		
<\$25,000	7 (35.0)	
\$25,000-\$39,999	1 (5.0)	
\$40,000-\$49,999	1 (5.0)	
\$50,000-\$74,999	4 (20.0)	
\$75,000-\$99,999	1 (5.0)	
\$100,000-\$124,999	3 (15.0)	
\$125,000-\$149,999	1 (5.0)	
Prefer not to say	2 (10.0)	

Value data are mean \pm SD or n (%).

"I've also really found some positive reinforcement and some great support from social media groups, both Instagram and on Facebook. So, that's been really good for me . . . There's someone in our group on Facebook that checks in with everybody's blood sugar

every day, and you kind of see where everyone's at." (ID 117, T2D, 1-year duration)

Several of the student and faculty participants referred to the support they received from the university's diabetes

community. Specifically, they mentioned the College Diabetes Network, in addition to the university's student organization dedicated to supporting students with diabetes on campus. The following quotations exemplified the positive and supportive community at the university.

"I definitely think joining DOSES [the university student group] has been helpful because it's easy to see that other people who go here are living with the same thing." (ID 101, T1D, 10-year duration)

"I'm getting involved with things like College Diabetes Network, meeting new people. I'm continuously meeting people who have type 1 diabetes as well, and it's just—it's nice to be able to talk with other people and share similar experiences we might have If you have a problem with your supplies or anything, you always know who to go to. You can always talk to someone. You're not alone with it, and it's nice to have that." (ID 106, T1D, 13-year duration)

Finally, multiple participants discussed the importance of mentorship, as well as mentoring others with diabetes. They described the role mentors played in encouraging positive self-care behaviors and everyday life advice.

"The person that told me about CDN [College Diabetes Network] was one of my biggest mentors, even to this day. I'll call her, and she gives me advice about how I'm running my group, and what—and it's just kind of nice, like she's always a source of encouragement for whenever I'm doing something, especially in the diabetes community She's doing things that I hope I can do in the future." (ID 100, T1D, 9-year duration)

Some participants, inspired by the positive role models in their life, felt it was necessary to give back to the diabetes community. They described volunteering to speak at local schools, serving as diabetes camp counselors, running local chapters of diabetes organizations, helping as diabetes peer educators, or traveling to other countries to provide diabetes education. For example, one participant spent time in local elementary and high schools mentoring children with diabetes.

"Being able to help other people who are recently diagnosed or are also living with it would definitely be a positive thing Having a conversation with them and just talking to them about—it doesn't even have to be about diabetes—but just knowing that there's

someone else there who has diabetes." (ID 101, T1D, 10-year duration)

Other participants described their experiences educating people about type 1 or type 2 diabetes. For example, this participant spoke at a national coaching conference to educate coaches on how to help athletes with diabetes.

"I've actually spoken at the national conference . . . about coaching the diabetic athlete, just to make coaches aware I think that it really helps the coaches become much more comfortable in dealing with a diabetic athlete. Hopefully, the diabetic athlete, they'll learn there's no real issues. 'If they occasionally get low or they show up high, here's what I got to do.' But, by and large, you're not going to have any real issues. I think by doing that, it helps future diabetics because then they don't get treated differently." (ID 118, T1D, 18-year duration)

Improved Health Behaviors

Nearly all of the participants ($n = 18$) reported positive changes in their health behaviors as a result of living with diabetes. Participants cited improvements in their eating habits and awareness of the carbohydrate content in foods. In their opinion, diabetes made them more aware of how certain foods affect their blood glucose values and overall well-being. As these participants explained:

"It's made me more conscious of how I treat my body, what I eat. Also, I know what's in my food from counting carbs I'm careful to look at my body, how I'm feeling. It makes me more aware of what's going on." (ID 100, T1D, 9-year duration)

"I'd say, now, I'm very conscious about what I eat. I like to say I have a pretty healthy diet. It's really helped me to manage that, and I need to keep a healthy diet in order to keep my blood sugar in check. It's really an encouragement to eat better and also to exercise a lot to keep blood sugar in range." (ID 106, T1D, 13-year duration)

Some participants shared examples of how small swaps in the foods they ate helped them improve their blood glucose values while still enjoying some of their favorite foods.

"And you don't want to have the roll or avoid the corn and swap that out for green beans or something like that." (ID 112, T2D, 11-year duration)

“I stay pretty strict about diet and just substitute turnips for potatoes . . . I’ve had conversations with friends that know I’m perhaps more diet-conscious than they are about, like, using the potatoes and turnips thing. I guess fewer carbs, I think in my mind is better for everybody.” (ID 115, T2D, 8-year duration)

Participants attributed engaging in regular physical activity to lowering and maintaining blood glucose values within their target range. Many participants used a combination of healthy diet and exercise, whereas others used exercise alone to manage their diabetes.

“I found, come spring, I had lost enough weight that I could run, so I started doing that. Got to where I did a 5K, and then eventually a 10K.” (ID 107, T2D, 2-year duration)

“I do make a very concerted effort to try to walk at least 2–3 miles at least three or four times a week.” (ID 111, T2D, 3-year duration)

For many of the participants, healthier eating and exercise helped them lose weight: “I guess finding the diagnosis gave me what I needed to do something about it. So, for the last year, I’ve dropped 80 lb, and [my] energy level has skyrocketed.” (ID 107, T2D, 2-year duration). These behavioral changes improved their emotional well-being, energy levels, and overall health status: “That is something that I factor in when I try to eat healthy and exercise regularly, I know that it also helps me to have better control, and so I feel better when I have better control.” (ID 108, T1D, 16-year duration). One participant also shared the benefit of healthy diet and exercise on mental health and how it helped to improve depression.

“Mental well-being is tied to a lot of things, and a good diet is part of it. When I was in my late 30s into my 40s, [I] was medicated for depression and anxiety . . . [It] definitely affected my well-being, and I think we get into that, ‘Okay, did the diabetes cause that, or is it a factor?’ You get into that tailspin, and then, you’re going to eat more Snickers bars. You’re going to tailspin into it, and for me, it was alcohol. And it was beer, high-carb stuff, and I’m certain that exacerbated the diabetes. [I] didn’t exercise . . . It [diabetes] is kind of a blessing in disguise, because I am doing more for myself because I’ve got something to keep track of. I would say definitely it’s helped, and I’ve got to think it’s helped with emotional outlook, too, because it’s all one body.” (ID 115, T2D, 8-year duration).

Positive Outlook and Personal Growth

Most participants credited their personal growth and a positive outlook to living with diabetes. All but one participant ($n = 19$) felt that their diabetes helped them grow as a person. For some, living with diabetes increased their empathy and compassion toward others.

“Growing up with this disease, I found out that I really, really, really care for people. I like to make sure that people are always in the best physical state of health and mind and psyche.” (ID 103, T1D, 12-year duration)

“Having empathy for others, too. I know that it’s not just other people who have diabetes, but other people who may have other chronic illnesses or something going on in their life.” (ID 106, T1D, 13-year duration)

For others, especially participants with type 1 diabetes, diabetes forced them to mature at an earlier age. They had more responsibilities (e.g., monitoring blood glucose levels, taking medications, and treating hypoglycemia) compared with their same-age peers.

“Yeah, the positive one was just growing up. It taught you self-discipline. I was diagnosed going into sixth grade. Throughout middle school and high school, I just found myself way more mature than all my friends. They were still goofing off and stuff, which is fine because you’re young. I felt like I had a huge responsibility with my health, and that made me grown up way, way quicker than others.” (ID 103, T1D, 12-year duration)

“I was older when I was diagnosed. I was 13. I feel like that made me grow up in a sense. I had to be more responsible than other teenagers. I felt like it was the end of the world when it happened, but I feel like I have a more positive outlook on things now. Everyone can have it worse. It’s not a competition. In that way, it made me grow up, too.” (ID 104, T1D, 9-year duration)

Still others believed that diabetes gave them the confidence to take care of themselves now and in the future.

“So, I think I just feel better or have more confidence that I’m doing something that’s going to benefit [me] when I’m 70 and 80 . . . It’s just a kind of a relaxed confidence that, oh, I’m doing the right thing, and it’s the best thing I can do for myself, and that will pay dividends down the road.” (ID 115, T2D, 8-year duration)

“I think I will move forward with the good work that I’m doing, and I’ll be able to be off insulin and take oral medication, which is exciting to me. So, I feel like there’s hope. I feel hopeful. I don’t feel really discouraged by diabetes. I feel like it’s been more positive for me than negative.” (ID 117, T2D, 1-year duration)

The majority of participants ($n = 15$) held a positive outlook about their diabetes. Diabetes was not viewed as a hindrance, but rather as an advantage. Diabetes improved their health, self-care behaviors, relationships, work or school, and personal disposition. Participants explained that they could do everything a person without diabetes could do and, in some instances, more.

“It’s not something bad to live with. People are like, ‘Oh, I’m so sorry.’ It’s not a big deal. I still make the most out of my life. Everything I want to do, I can do. People like to think that you shouldn’t eat this or something, but I can do whatever I want with an insulin pump or even if you’re on the shots. Nothing holds me back from doing anything, and it’s actually made me a better student. It’s made me better with my diet and better getting me to go to the gym.” (ID 106, T1D, 13-year duration)

Moreover, participants recognized that diabetes was a part of their lives, but it did not define who they were or what they could accomplish in life.

“Diabetes is definitely a part of my life. It is literally impossible for me to separate it. But I don’t think it’s what defines who I am as a person. It’s just this thing I have to deal with.” (ID 108, T1D, 16-year duration)

“It took me a while to realize this is the rest of my life, but now looking back, I’m happy this is what’s happened. It’s part of who I am. The things that I’ve been doing with it have made a positive impact in general on my own life.” (ID 101, T1D, 10-year duration)

“The one thing that I’ve always told people, they would say I’m ‘a diabetic.’ No. You ‘have diabetes,’ and it’s a disease, and you can manage it. Do not become the disease. That was the one message I did give. ‘Oh, you’re a diabetic?’ ‘No, I have diabetes.’ That is not who I am. Do not let it become you. I think holding that in your mind then, because it beats you if you become ‘a diabetic.’ ” (ID 119, T2D, 26-year duration)

Lastly, several participants expressed optimism for their future. They recognized that successful diabetes

management helped them feel better and cope with uncertainty.

“So, there’s a sense of optimism, of figuring out, ‘Okay, I don’t know what the future is, but it’s going to be good.’ I said that’s the main lesson I’ve taken away from the diabetes thing right now . . . I feel so much better.” (ID 107, T2D, 2-year duration)

“I have a very positive life, so is my life positive because of diabetes? Maybe in some ways, because it’s made me adaptable, and it makes me a good planner and maybe more compassionate to others . . . Everything is positive to me. I don’t know how to really explain that. I don’t know what’s in store for me, but I know whatever it is, it’s going to be a blessing.” (ID 109, T1D, 42-year duration)

Advocacy for People With Diabetes

The majority ($n = 14$) of the participants shared stories of advocacy about themselves and others with diabetes. For example, one participant discussed policy issues on Capitol Hill in Washington, DC.

“I think through working with the diabetes community, I have been able to be an advocate, not only for myself . . . but I also advocate for others and can help others navigate whatever system they’re going through. I talk to representatives about issues going on . . . I advocate on a political level. Through the Diabetes Patient Advocacy Coalition, I have [had] the opportunity to go to Washington, DC, and actually get training and experience on how to be an advocate, which I definitely would never have that experience if I wasn’t diagnosed and have this passion. It’s really awesome to kind of learn about what issues are not only affecting me, but so many other Americans and people with diabetes.” (ID 100, T1D, 9-year duration)

Participants took on the role of advocating for key policy issues such as lowering the cost of insulin and providing insurance coverage for preexisting conditions. In addition, participants recognized that education and increasing awareness about diabetes was something within their power: “We talk about different events we could set up for getting diabetes awareness out and doing fun things together [in a student organization].” (ID 106, T1D, 13-year duration).

Beyond advocacy, all 20 participants offered advice for people newly diagnosed with diabetes. One common

sentiment was reassurance that a person's life was not over because of this diagnosis.

"Their life isn't over. When I was diagnosed, [I thought] my life was over. It's definitely not at all. It's helped me with so many opportunities." (ID 101, T1D, 10-year duration)

"It is not the end of the world . . . It keeps you aware of your body and your food intake and your habits, and it kind of makes you more whole as a person, I feel." (ID 110, T1D, 1-year duration)

If people newly diagnosed felt overwhelmed, participants stressed the basics of diabetes self-management. For example, one person remembered the 15/15 rule when experiencing hypoglycemia.

"This is such a little thing, but it goes such a long way, and it's one of the fundamentals of when you're going low. They always tell you the 15/15 rule. You eat 15 [g] carbs, [and] wait 15 minutes." (ID 103, T1D, 12-year duration)

Others emphasized the habitual nature of diabetes self-management. They explained that diabetes could be managed by forming positive diet, physical activity, and blood glucose monitoring behaviors.

"I would tell them to not be afraid. I would tell them that this is an opportunity, especially with type 2 diabetes. I think that the changes that we make in our life directly contribute to our success in type 2 diabetes. Making some of those changes that we didn't make before . . . just controls it. Take your life [in] your hands." (ID 117, T2D, 1-year duration)

"I think with diabetes, it's a habitual disease. It's about getting into good habits." (ID 108, T1D, 16-year duration)

Finally, participants emphasized that diabetes was a manageable condition. With the support of the diabetes community and a positive outlook, they said, people with diabetes had a promising future.

"There's more to come, and there's a great community out there willing to support you." (ID 100, T1D, 9-year duration)

"I feel like you have all the control in the world . . . The good news is that you've got pretty much total control

in managing this thing, and it's not that hard." (ID 115, T2D, 8-year duration)

Discussion

In this qualitative study, we explored positive experiences of people living with type 1 or type 2 diabetes. Our findings highlight the importance of having a positive, supportive network of family, friends, and community. Participants recounted story after story of positive experiences with people exemplifying support, encouragement, advice, and mentorship. In addition, participants believed diabetes improved their health, self-care behaviors, and outlook on life. Furthermore, many participants recognized that diabetes contributed to their personal growth. They attributed increases in empathy, compassion, confidence, and maturity to living with diabetes. Finally, many participants assumed the role of advocate, educating people about diabetes and recommending policy changes for diabetes insurance coverage.

All participants commented on the value of community and peer support from many sources in their lives, including family, friends, classmates, coworkers, and the online diabetes community. Participants' support systems helped them manage hypoglycemia and hyperglycemia, as well as cope with the many challenges of diabetes. Social support is well documented in the diabetes literature as being associated with better physical and mental health (32,33), and it may have a buffering effect on diabetes distress, self-care, and A1C (34–36).

Additionally, several participants referred to the supportive diabetes community at the university as well as the online community. Both the university and online communities offered peer support, which is defined as support from an individual who has experiential knowledge in the specific behaviors and/or practices of the target population (37). Peer support has been shown to improve diet, physical activity, blood glucose monitoring, and medication-taking in adults with diabetes (38,39).

The effectiveness of peer support is attributed to the reciprocal relationship formed between people sharing similar life experiences (37,40), such as what occurs in student organizations on campus and within the online diabetes community. This community provides advice, tips, and encouragement about all aspects of diabetes management. Thus, communicating the importance of community and peer support to people with diabetes should be emphasized during clinical appointments and DSMES. Similarly, for individuals who experience sabotaging behaviors or miscarried helping from family members (41,42),

clinicians and educators should engage family members in discussions about the negative influence of nonsupportive behaviors on diabetes self-care and A1C (43).

The majority of participants held a positive outlook about their diabetes, viewing it as a benefit rather than a detriment. These participants felt optimistic about their future. Optimism has been linked to higher levels of engagement coping, or taking an active role in one's health, and lower levels of avoidance coping (44). Research in nondiabetes populations has shown that optimism is associated with better mental and physical well-being (44,45). A cross-sectional study by Zhao et al. (46) found that diabetes self-care behaviors, specifically following a healthy diet, getting physical activity, taking medication, self-monitoring blood glucose, and performing foot care, were associated with optimism. Although more research is needed to determine the cause-effect relationship between diabetes self-care and optimism, these initial findings may motivate people with diabetes to improve their diabetes self-care behaviors to improve their subjective well-being (46).

With these findings in mind, clinicians could encourage cognitive restructuring techniques that challenge negative thoughts and reframe them so they are more positive (47). For example, for people with moderate levels of diabetes-related regimen distress, clinicians could reframe their frustrations with managing self-care by asking them to view their diabetes as a built-in reminder to take care of their health and mental well-being.

The qualitative findings also suggest that a longer diabetes duration and healthy coping may contribute to participants' positive experiences. The majority of participants had a diabetes duration ≥ 10 years (mean 12.9 ± 10.3), which provides adequate time to accept the diagnosis and adapt to the self-care plan. Furthermore, the four themes identified in this study reflect healthy coping or "responding to a psychological and physical challenge by recruiting available resources to increase the probability of favorable outcomes in the future," as defined by panel members from the American Association of Diabetes Care & Education Specialists (48). Participants performed healthy self-care behaviors, joined support networks, and engaged in problem-solving behaviors (i.e., mentoring and advocacy) (49–51). Importantly, many participants revealed that they developed healthy coping over time, with several stating that they struggled to accept their diabetes in the beginning, but later realized it was an opportunity for them to learn and grow. The interplay between duration and coping is a hypothesis that should be tested via longitudinal research examining self-care

behaviors, coping, social support, and optimism at different stages in the life course of diabetes (i.e., at the onset of diabetes, during health maintenance, at the onset of complications, and when complications dominate) (52).

Limitations

Study limitations include homogeneity with regard to several important sociodemographic variables, including race/ethnicity, education, income, employment, insurance coverage, and access to health care services. Although the all-White study sample is representative of the racial and ethnic distribution of southeastern Ohio (95.0% White [53]), it is not reflective of the prevalence of diagnosed diabetes in the United States, which is highest among American Indians/Alaska Natives, people of Hispanic origin, and non-Hispanic Blacks (1). Furthermore, the majority of participants were either students or retired, well-educated, insured, and living above the U.S. federal poverty level. These sociodemographic characteristics are notable considering their association with improved diabetes outcomes, reduced mortality risk, and increased access to health care services (54–58).

Thus, the qualitative findings in this study may not be transferable or generalizable to people not represented in the sample. For example, a person of Hispanic origin with limited English proficiency who was born outside of the United States is more likely to have limited access to primary care, language discordance, a lack of cultural proficiency with health care providers, diabetes complications, and psychosocial difficulties (59–65). For these reasons, such individuals may not view their diabetes as positively as the participants in this study. Thus, future research with a larger, more diverse sample is necessary to explore both positive and negative experiences with diabetes.

Additional limitations to the study include the small sample size and participant self-selection, both of which limit the transferability of the findings. Individuals who volunteered to participate may have had more positive experiences with diabetes compared with people who did not participate.

The purpose of qualitative research is to understand a phenomenon and generate ideas for hypothesis-testing rather than to test hypotheses (66). Consistent with the philosophical underpinnings of qualitative research, purposive sampling identifies participants who are able to richly describe their positive experiences with diabetes. Purposive sampling techniques are useful in learning

more about how a group (i.e., people with diabetes) thinks about and experiences a given phenomenon (25).

Such purposeful sampling is different from statistically driven research, which relies on randomness to generalize findings from a small sample to a larger population. The logic of qualitative sampling rests not on generalizability, but on the notion of saturation, that is, the point at which no new information is obtained. Therefore, sample size is not a criterion for evaluating the rigor of the sampling strategy, but rather, for evaluating the adequacy and the comprehensiveness of the findings. A good sample size for individual interviews is between 15 and 20 participants (25).

For the purposes of this qualitative study, our goal was to find participants who had specific positive experiences with type 1 or type 2 diabetes; therefore, participants without positive diabetes experiences were not captured in the data.

Next, self-reported data are vulnerable to social desirability bias. To minimize bias, the researchers informed participants that their responses were confidential and could not be linked back to their personal identity. Furthermore, the investigators emphasized the voluntary nature of participation and explicitly informed participants that their responses had no bearing on their diabetes care.

Conclusion

Research that recognizes and understands the positive experiences of living with diabetes presents a unique opportunity for clinicians and educators to reframe the negative messages commonly shared with people with diabetes. Our participants focused on positive and supportive experiences with their peers and community, improved health behaviors, personal growth, and engagement in diabetes advocacy. Communicating positive experiences with people with diabetes, especially those who have accepted their diabetes and report few barriers (e.g., financial stress or low social support), may promote optimism and, in turn, improve self-care, mental well-being, and physical health. Additional research is needed to examine the associations among social support, coping, optimism, diabetes self-care, and physical and mental health in adults with type 1 or type 2 diabetes.

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DUALITY OF INTEREST

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

AUTHOR CONTRIBUTIONS

Both authors provided substantial contributions to conception and design, acquisition of data and data analysis, and interpretation of data; drafted and revised the article critically for important intellectual content; and gave final approval of the version to be published. Both authors are guarantors of this work and, as such, had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

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