



Similarities and Differences in Diabetes Diagnosis Stories Among Adults With Type 1 or Type 2 Diabetes in Appalachian Ohio

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This qualitative study examined adults' recollections of their reactions to their diabetes diagnosis and explored the similarities and differences among those diagnosed with type 1 versus type 2 diabetes. Based on semistructured interviews, the authors identified three themes: 1) shared emotional reactions of fear, sadness, confusion, and worry; 2) perceived differences in expressing concerns for diabetes complications; and 3) differences in perceiving the diagnosis as a surprise versus an inevitability. How health care professionals (HCPs) deliver diabetes diagnoses may be crucial to individuals' acceptance of the condition and coping strategies. HCPs should consider assessing people's emotional reactions to their diagnosis.

Diabetes is a major public health concern in the United States, with 11.3% of the national population affected by this chronic condition (1). In Appalachian Ohio, the diabetes prevalence is nearly double the national average (19.9%) (2). Here, people face numerous challenges affecting their ability to manage diabetes effectively, including limited access to specialty care, financial insecurity, lack of transportation, food insecurity, underemployment, and lower educational attainment (3–5). Additionally, people from Appalachian Ohio experience higher rates of specific psychosocial issues, including clinically significant depressive symptoms and diabetes distress (i.e., the negative emotional experience of having to manage a chronic, progressive condition such as diabetes) (6–8). These psychosocial issues are often associated with reduced engagement in diabetes self-care behaviors, potentially leading to long-term complications (9).

For many people, receiving a diabetes diagnosis is a life-changing event that can affect overall well-being. A diagnosis of any chronic condition can evoke a range of emotions, including denial, fear, stress, and sadness (10). Previous research has shown that the diagnosis of a chronic condition can result in a profound sense of identity loss and lead people to perceive negative physical, cognitive, and emotional changes within themselves (11).

The presence of emotional changes at diagnosis may affect people's future psychological adjustment and management of their chronic condition. For example, a study investigating the connection between the reaction to a breast cancer diagnosis and subsequent mental adjustment revealed that avoiding the diagnosis was linked to greater emotional distress, whereas active acceptance and confrontation were associated with improved well-being (12). Additional studies exploring diagnoses of gastrointestinal cancer demonstrated that people who displayed optimism toward combating their diagnosis exhibited reduced levels of anxiety and depression (13). Thus, identifying people's emotional reactions and attitudes toward their diagnoses may help in developing effective coping mechanisms and preventing the development of comorbid psychosocial issues.

Moreover, at the time of diagnosis, people with chronic conditions such as diabetes may have limited emotional support beyond what their health care professionals (HCPs) offer. For this reason, how HCPs deliver diagnoses is a crucial part of people's emotional coping (14). Improving the delivery of diagnoses by providing emotional

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support and ensuring that people have sufficient resources for managing their condition early on can improve their adjustment to the condition and lead to better treatment outcomes (15,16). Additionally, facilitating open dialogue for people with chronic conditions to express their own distinct reactions to a diagnosis and offering to listen and support them are crucial aspects of quality patient care (17). However, minimal research has focused on the experiences of people diagnosed with diabetes and the potential impact their reactions have on their well-being and adjustment to the condition. Furthermore, diagnosis experiences may differ between people with type 1 diabetes and those with type 2 diabetes. Recognizing and understanding these differences may assist HCPs in tailoring care and interventions to meet individuals' needs.

The purpose of this qualitative study was to examine people's experiences of living with type 1 or type 2 diabetes. For this study, our guiding research question included people's recollection of their reactions to their diabetes diagnosis or the diabetes diagnosis stories they embraced. We then explored the similarities and differences in these stories between those diagnosed with type 1 diabetes and those with type 2 diabetes. By better understanding the lived experiences of people with diabetes, we aim to provide valuable insights that may be used for developing more effective clinical support and resources.

Research Design and Methods

Research Design

We used narrative inquiry to identify similarities and differences in individuals' type 1 and type 2 diabetes diagnosis stories (18). Narrative inquiry reveals unique perspectives to gain a better understanding of individuals' lived experiences. For these diagnosis stories, we asked people with diabetes to describe in detail how they first learned they had diabetes. Thus, narrative inquiry was an ideal approach to examine individual diagnosis stories.

Documenting these lived experiences may provide insight into how HCPs can deliver diabetes diagnoses while supporting individuals' emotional well-being. The Ohio University Office of Research Compliance approved the protocol and all recruitment procedures and materials (Institutional Review Board #18-X-232). All participants provided informed written consent before participating. We adhered to the Consolidated Criteria for Reporting Qualitative Research.

Sample

Participants were recruited from southeastern Ohio, which is part of Appalachia, a cultural region in the eastern United States that stretches from Mississippi to New York. It is a rural, underserved region with a high prevalence of type 2 diabetes. Exclusion criteria included age <18 years, inability to read or write in English, and diabetes diagnosis that could not be clearly identified as type 1 or type 2 diabetes. We recruited participants via emails to the University Listserv, flyers at county health departments and local stores, social media posts, and word of mouth. The study opened on 1 August 2018 and closed on 31 March 2020. Participation in the study was voluntary.

Data Collection

The semi-structured interview guide was developed by the research team. The interview guide was pilot-tested with three participants before the start of data collection. Two experienced qualitative researchers conducted all interviews, asking participants open-ended questions about their diagnosis, how they manage their diabetes, their frustrations and/or worries with the condition, and the emotional impact of living with it (Table 1). We used directive probes to clarify questions and elicit additional information from the participants. In addition, we kept field notes to capture key points (i.e., written accounts of what happened during interviews) and observations (e.g., participants' non-verbal communication, expressions, and behaviors) during the interviews.

Next, we used the concept of information power to guide sample size; information power focuses on the amount of new knowledge generated rather than the number of participants (19). We conducted 46 in-person interviews at conference rooms and university offices and two telephone interviews to accommodate participants' mobility problems. Interviews lasted between 20 and 120 minutes. For participating in the interview, we provided a \$25 gift card or \$25 in cash as human participant compensation.

All interviews were digitally audio-recorded and transcribed verbatim. We performed quality checks of the transcribed files to validate the transcriptions. We removed participants' names and identifiers to protect confidentiality. Importantly, none of the research team members had a prior relationship with any of the study participants.

TABLE 1 Semi-Structured Interview Guide

Interview Questions

1. How did you first learn that you had diabetes? Probe: How did the diagnosis make you feel?
2. How do you manage your diabetes? Probe: Can you be more specific about the things you do?
3. What is the hardest thing about having diabetes? What have you struggled with?
4. Do you ever feel frustrated with your diabetes self-care (e.g., diet, exercise, medications, blood glucose monitoring)? Please explain.
5. Do you worry about the future and the possibility of developing complications? Please explain. Probe: What are your biggest concerns or worries about having diabetes?
6. Do you have concerns about the quality of medical care and the cost of that care? Please explain.
7. Do you perceive a lack of support from family members and/or friends? Please explain.
8. Diabetes can affect people's emotions. Do you think your diabetes and emotions are related? Please explain. Probe: How does diabetes affect your emotions? Negatively or positively? Probe: Do these emotions get in the way of your diabetes management? Please explain. Probe: What helps you manage your emotions and diabetes?
9. What recommendations do you have for us to better help you take care of your diabetes?
10. Is there anything else you can tell me about your well-being and diabetes?

Data Analysis

The multidisciplinary research team, consisting of a pre-medical student, a clinical psychologist, and a behavioral diabetes researcher with a doctorate degree, analyzed data using coding reliability thematic analysis, which involves identifying codes and themes based on agreement among multiple coders (20). All research team members had formal training in qualitative research and conducted the analysis.

Our team generated initial codes by reading and familiarizing ourselves with the data. Then, we independently marked and categorized text with our initial codes (21). Next, we met to review our coded data and resolve any discrepancies via group consensus. The Cohen's κ coefficient between the two coders was 0.929, indicating almost perfect agreement (22). One member of the research team entered the coded transcripts in NVivo software (QSR International, Victoria, Australia).

Finally, we derived themes from the data with a thematic map to visualize how our codes overlapped with each other to form an overarching theme. Our themes described similarities and differences in participants' stories of being diagnosed with type 1 or type 2 diabetes.

Rigor

To support credibility (i.e., validity), investigators with expertise from different disciplines were triangulated. Analyst triangulation provided a check on selective perceptions to identify blind spots in the analysis (23). Furthermore, four participants reviewed the findings to support participant corroboration; we did not provide these participants with their own transcripts. To support dependability (i.e., reliability), a researcher not involved with the study conducted an external audit to examine the research process and determine whether the findings were supported by the data (23). Finally, confirmability (i.e., objectivity) was supported through tracking the decision-making process (23).

Results

Sample Characteristics

A total of 48 participants took part in the interview process. The average age of participants was 45.8 \pm 21.7 years (Table 2). Participants with type 1 diabetes accounted for 39.6% of the total sample ($n = 19$), with ages ranging from 18 to 63 years (mean 31.4 \pm 15.9 years). Those with type 2 diabetes made up 60.4% of the total sample ($n = 29$), with ages ranging from 19 to 85 years (mean 55.3 \pm 19.8 years). Among the participants, 56.3% ($n = 27$) identified as female and 43.8% ($n = 21$)

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TABLE 2 Participants' Demographic Characteristics (*N* = 48)

Variable	Type 1 Diabetes	Type 2 Diabetes	Total
Age, years	31.4 ± 15.9	55.3 ± 19.8	45.8 ± 21.7
Gender			
Female	10 (52.6)	17 (58.6)	27 (56.3)
Male	9 (47.4)	12 (41.4)	21 (43.8)
Nonbinary	0 (0)	0 (0)	0 (0)
Other	0 (0)	0 (0)	0 (0)
Race			
American Indian or Alaska Native	0 (0)	0 (0)	0 (0)
Asian	0 (0)	2 (6.9)	2 (4.2)
Black or African American	0 (0)	0 (0)	0 (0)
White	19 (100)	25 (86.2)	44 (91.7)
Two or more races	0 (0)	2 (6.9)	2 (4.2)
Other	0 (0)	0 (0)	0 (0)
Education level completed			
High school or lower	3 (15.8)	4 (13.8)	7 (14.6)
Current undergraduate or graduate student	9 (47.4)	2 (6.9)	11 (22.9)
2-Year college degree	1 (5.3)	3 (10.3)	4 (8.3)
Some college, did not finish	0 (0)	2 (6.9)	2 (6.9)
4-Year college degree	1 (5.3)	5 (17.2)	6 (12.5)
Some graduate work	2 (10.5)	1 (3.4)	3 (6.3)
Advanced graduate work or doctorate	3 (15.8)	12 (41.4)	15 (31.3)
Diabetes duration, years	17.4 ± 14.7	10.8 ± 11.2	13.4 ± 12.9
A1C, %	7.6 ± 1.5	7.7 ± 1.9*	7.7 ± 1.8
BMI, kg/m ²	26.1 ± 6.4	32.6 ± 7.7	30.0 ± 7.8

Data are *n* (%) or mean ± SD. *One missing value.

identified as male, and 91.7% (*n* = 44) identified as White. Participants' average A1C was 7.7 ± 1.8%, with values ranging from 5.4 to 15%. The mean duration of diabetes among the participants was 13.4 ± 12.9 years.

Thematic Analysis

We identified three themes using coding reliability thematic analysis. These themes captured participants' real-life experiences and emotional reactions around receiving their diabetes diagnosis. For each theme, we discovered similarities and differences between individuals with type 1 diabetes and those with type 2 diabetes (Table 3). Sample quotations are identified by transcript identifiers and participants' diabetes type and age. The following themes were identified.

Theme 1: shared emotional reactions of fear, sadness, confusion, and worry

Participants with either type 1 or type 2 diabetes described their diagnosis as a major life event. When asked how they felt at diagnosis, most participants responded with one-word reactions, such as "depressed,"

"upset," "scared," "nervous," "traumatic," "worried," "terrified," "panicked," "disappointed," "discouraged," or "in denial." With additional probing, participants shared that they felt overwhelmed, confused, and uncertain about their diagnosis. Some participants said they knew very little about diabetes, so they felt fearful and scared. For them, the experience of receiving the diagnosis, along with the overload of information related to its management, was a lot to take in, as evidenced by the following quotations.

"I didn't know what diabetes was, so I was like, 'What's going on?' I knew I had to go to the hospital and stay there. It was just very stressful and alarming to me. Not knowing what the diagnosis was made me scared." (ID 110, type 1 diabetes, 20 years of age)

"I was pretty nervous. I didn't know what I was getting into. I just knew that it was going to affect, for me, what sounded like the rest of my life. I would say I just was kind of confused and just trying to understand how everything was going to be different." (ID 115, type 1 diabetes, 20 years of age)

TABLE 3 Summary of Qualitative Themes, Descriptions, and Observed Similarities and Differences Between Participants With Type 1 Diabetes and Those With Type 2 Diabetes

Theme	Description	Similarities Observed Between Participants With Type 1 Diabetes and Those With Type 2 Diabetes	Differences Observed Between Participants With Type 1 Diabetes and Those With Type 2 Diabetes
1. Shared emotional reactions of fear, sadness, confusion, and worry	This theme describes participants' emotional reactions to their diagnosis of type 1 or type 2 diabetes.	Participants with either type 1 or type 2 diabetes expressed negative emotional reactions to their diagnosis. Many described their diagnosis as one of the worst experiences of their life. Participants also described feeling different from people without diabetes after their diagnosis.	No differences were observed in participants' emotional reactions to their diabetes diagnosis.
2. Perceived differences in expressing concerns for diabetes complications	This theme describes participants' concerns about diabetes complications at diagnosis.	No similarities were observed in expressing concerns about diabetes complications.	Participants with type 2 diabetes expressed concerns about long-term complications of diabetes. Participants with type 2 diabetes likened their diagnosis to a death sentence or the end of the world. Participants with type 1 diabetes did not describe worries about complications.
3. Differences in perceiving the diagnosis as a surprise versus an inevitability	This theme describes participants' expectations of developing diabetes.	No similarities were observed in expectations of a diabetes diagnosis.	Participants with type 2 diabetes expected their diagnosis because many had prediabetes and/or a family history of type 2 diabetes. For participants with type 1 diabetes, the diagnosis was a surprise to them.

“It wasn’t until about 4 or 5 weeks later when I saw an endocrinologist, and I felt like a train hit me, and I realized that diabetes wasn’t just a word. It was a problem for me.” (ID 202, type 2 diabetes, 47 years of age)

“It scared me. It felt like the end of the world. He [the doctor] sent me to the, what do you call it, the [diabetes educator]. She showed me how to use the needle. She just showed me how to do it. Didn’t even take the needle out; just told me what to do on a piece of fruit, without injecting the fruit, and sent me home with the stuff.” (ID 218, type 2 diabetes, 61 years of age)

Participants emphasized the worry and fear that arose from integrating new self-care behaviors into their daily lives, such as monitoring blood glucose levels and administering insulin. For many, fingersticks and insulin injections created a sense of unease and/or discomfort

until they got accustomed to the behaviors or were able to switch to an insulin pump and/or continuous glucose monitoring system. Participants also described feelings of apprehension and anguish with their diagnosis because they knew they would have to manage diabetes for the rest of their lives. In other words, their lives were forever going to be different moving forward. From now on, participants would have to account for their diabetes in future decisions. The following quotations demonstrate the emotional experience of learning how to live with and manage their diabetes.

“And, I remember it being just very traumatic in the beginning, like learning I had to poke myself every day and give myself shots, because I started out being on injections, and now, I have an insulin pump. But I started out doing that, and it was terrifying.” (ID 105, type 1 diabetes, 21 years of age)

“I remember thinking that this was going to be a lot more difficult than I first thought, just after he went through all the things I needed to make sure I did. So, yeah, I mean, just my kind of discomfort on knowing what this means and that sort of thing.” (ID 103, type 1 diabetes, 24 years of age)

“It’s always there. You always have to think about it. You always have to plan for it. It’s really a big nuisance, and it just never goes away, and you can’t forget about it because you’re constantly monitoring, taking medicine.” (ID 210, type 2 diabetes, 40 years of age)

The worries and fears about managing diabetes, combined with the chronicity of the condition, led some participants to label their diagnosis as one of the worst experiences of their life. As one participant said:

“I don’t know if there are any experiences that are worse than that.” (ID 111, type 1 diabetes, 24 years of age)

For these participants, the struggle was in learning to accept their new diagnosis while knowing that their lives were different from that point forward. Many participants worried about whether they would be able to do the same things or feel like the same person as before their diagnosis, as evidenced by the following quotations.

“The main struggle for me [was] wondering if I could still do the things that I could previously do.” (ID 102, type 1 diabetes, 60 years of age)

“It was going to affect, for me, what sounded like the rest of my life.” (ID 115, type 1 diabetes, 20 years of age)

“The hardest thing for me has been feeling like my life will never be the same. I don’t even feel like the same person.” (ID 202, type 2 diabetes, 47 years of age)

Furthermore, a few participants felt that their diabetes diagnosis made them different from everyone else.

They described their diagnosis as a defining moment in their lives that created an invisible distinction between them and their friends and family, as shown in the following quotations.

“I felt entirely different than any of my other family members It almost made me feel ostracized.” (ID 102, type 1 diabetes, 60 years of age)

“Every time I’d go to a sleepover, my mom would have to come and say I have type 1 diabetes and this is

what happens if their blood sugar is low That’s when I realized, because when my friends would come over to my house, their parents were like, ‘Here you go. Here’s your sleeping bag’ and ‘Pick you up tomorrow.’ I noticed nobody else had explanations for when they had to sleepover, but whenever I went someplace, my mom would have to explain how I was. So, I think that’s when it started to sink in that I have diabetes. I have something that none of my friends have.” (ID 105, type 1 diabetes, 21 years of age)

“So, I don’t really know how to handle it. I don’t know who to tell. I don’t think people understand. It’s really hard not knowing. Everybody just thinks life is all the same, and on the outside you look the same, but they have no clue what’s going on in the inside. I’m not a different person, but you feel like one, and nobody gets that.” (ID 202, type 2 diabetes, 47 years of age)

Finally, although the majority of participants expressed negative emotions related to their diabetes diagnosis, six of the 48 participants voiced neutral feelings toward their diagnosis. These participants stated that their diagnosis did not worry or upset them.

“I wasn’t really that worried about it.” (ID 108, type 1 diabetes, 30 years of age)

“It didn’t really bother me.” (ID 229, type 2 diabetes, 74 years of age)

Theme 2: perceived differences in expressing concerns for diabetes complications

When describing reactions to their diabetes diagnosis, participants with type 2 diabetes frequently expressed concern about chronic complications, whereas those with type 1 diabetes did not. Many participants with type 2 diabetes described watching their friends and family members with diabetes experience chronic complications such as nephropathy, retinopathy, and lower-extremity amputations. As these participants explained:

“I broke out crying because I had just known a couple of people that had had their legs taken off and it was all bad.” (ID 222, type 2 diabetes, 75 years of age)

“Concerned because my mother had it and had all sorts of complications from it.” (ID 223, type 2 diabetes, 71 years of age)

“Seeing what it does to my family, and I know a bunch of my family members passed away from it.” (ID 225, type 2 diabetes, 19 years of age)

These participants' experiences with diabetes complications may have contributed to their concerns about developing complications in the future. Moreover, these prior experiences with chronic complications may explain why some participants likened their diagnosis to a death sentence or "the end of the world."

"I was by myself in that room, and I thought, 'This is awful. This could be a death sentence. I could lose a leg. I could go blind. What's going to happen to me?'" (ID 208, type 2 diabetes, 70 years of age)

"I was a paramedic for 16 years, so I've seen the effects diabetes has—amputations, kidney problems, dialysis—kind of feels like a death sentence when you first get diagnosed." (ID 210, type 2 diabetes, 40 years of age)

"I honestly was scared because I thought I was done for, and I really didn't know what it was at the time." (ID 225, type 2 diabetes, 19 years of age)

Theme 3: differences in perceiving the diagnosis as a surprise versus an inevitability

Nearly all of the participants with type 1 diabetes called their diagnosis a complete surprise, with the exception of three participants who noted that they had family members with type 1 diabetes. Many of these participants expressed initial feelings of shock and denial when they were first diagnosed. In their descriptions, they questioned why they developed this condition, as opposed to others. Participants who were diagnosed in youth and/or those who perceived themselves to be healthy and active found it particularly difficult to grasp their new diagnosis. This sense of disbelief may have affected their ability to accept the diagnosis, as shown in the following quotations.

"I've always been healthy and going and going and going. And no high blood pressure, no problems, no nothing. When she [the doctor] said that, it was just a total shock, and what was I going to do. That's what I thought. 'Oh, lord, what [do I] I do now? What do I do?'" (ID 117, type 1 diabetes, 50 years of age)

"I was just like, 'Why me? Out of all the people in the world, why did this have to happen to me?' I've been fine. I've never really had any serious problems before that. So, it was just a huge shock to me." (ID 109, type 1 diabetes, 20 years of age)

"I was really in denial about it, I think, at first. I didn't want my closest friend to know about it because I

think it was like it was such a shock to myself that I couldn't accept it myself." (ID 111, type 1 diabetes, 24 years of age)

Conversely, most participants diagnosed with type 2 diabetes did not express any element of surprise regarding their diagnosis. Most participants with type 2 diabetes revealed that they had prediabetes and/or a family history of type 2 diabetes, which led them to expect a diagnosis. Furthermore, many believed that their diagnosis was inevitable or predetermined because of their family history.

"Not terribly surprised because I was so heavy at that point, and my dad has diabetes. I have several grandparents with diabetes, so it wasn't a huge surprise. I'm pre-inclined for it." (ID 211, type 2 diabetes, 39 years of age)

"I had suspicions because it's a big thing in my family, and I was with a former family doctor and in this very building, and I said—I think I'm sure I was around 45 or so or late 40s—and I said, 'You should probably test me because of my history,' and sure enough, he discovered that." (ID 203, type 2 diabetes, 65 years of age)

Discussion

In this qualitative study, we explored diagnosis stories from adults with type 1 or type 2 diabetes. Nearly all participants expressed similar emotional reactions to their diagnosis, including feelings of fear, sadness, confusion, and worry. Additionally, participants with either type 1 or type 2 diabetes also described their diabetes diagnosis as a major life event, with several stating that their life was never the same after their diagnosis. Interestingly, only participants with type 2 diabetes expressed worry and concern about long-term complications when asked about their diagnosis. Furthermore, the majority of participants with type 2 diabetes reported that they expected their diagnosis, whereas most participants with type 1 diabetes described their diagnosis as a surprise. Identifying similarities and differences in how people experienced their diagnosis of type 1 or type 2 diabetes may help HCPs tailor their messaging and the support resources they offer when giving diagnoses.

Previous research has shown that the diagnosis of a chronic condition can elicit a variety of emotions and unique reactions (24). Our study revealed similar emotional reactions in participants with type 1 or type 2

diabetes, demonstrating the profound impact of a diabetes diagnosis on individuals' life. These findings suggest that the psychosocial effects of diabetes begin at the moment of diagnosis, encompassing emotions such as fear, sadness, confusion, and worry.

Because type 1 diabetes, sometimes called "juvenile diabetes," is associated with a younger age at diagnosis, it is of interest that studies also have shown that younger age at the time of a type 2 diabetes diagnosis is associated with higher levels of depressive symptoms and diabetes distress (25–27). Thus, HCPs need to pay close attention to patients' age when giving diagnoses and to realize that patients' developmental status, as well as their family's reactions to the diagnosis, are of great importance. Prior research has investigated diabetes self-management and glycemia in type 1 diabetes across the adult life span (28), and a 2014 American Diabetes Association position statement set forth a developmental psychological life span approach for type 1 diabetes (29). This approach acknowledges each developmental stage (i.e., childhood, adolescence, emerging adulthood, mid-adulthood, and late adulthood) and considerations for each stage, which may guide HCPs' diagnostic and treatment decisions for people with either type 1 or type 2 diabetes. Importantly, the use of a developmental framework also has been seen as important in other chronic illnesses that may begin in childhood and are present throughout the life span (30). Based on our study, we offer suggestions for HCPs when facing people newly diagnosed with type 1 or type 2 diabetes that include diagnostic considerations using a developmental perspective (Supplementary Table S1).

Interestingly, our findings showed that people with either type 1 or type 2 diabetes reported many similar emotional responses. We found that different responses to the diagnosis were based on prior knowledge or experience of vulnerability to getting type 2 diabetes or its diabetes complications. For our participants with type 2 diabetes, the diagnosis may have been expected because type 2 diabetes has a stronger link to family history and lineage than type 1 diabetes; studies of twins have shown that genetics play a very strong role in the development of type 2 diabetes (31). Therefore, participants with type 2 diabetes may have heard about the inevitability of getting type 2 diabetes from their family members. On the other hand, it was a surprise for most participants diagnosed with type 1 diabetes because family history did not contribute to their expectations.

Another observed difference among our participants is that those with type 2 diabetes seemed to have extreme fear of diabetes complications, whereas those with type 1 diabetes did not mention complications. We speculate that observing or hearing about family members' experiences of complications again may account for these differences. Supplementary Table S1 offers broad clinical suggestions from a developmental perspective beginning with adolescence rather than childhood because of lower rates of type 2 diabetes in childhood. In this table, we emphasize the need to pay particular attention to the psychosocial realm and to inquire about emotional reactions, have more frequent follow-up to assess psychological functioning for those with psychosocial concerns, and make needed referrals to mental health professionals.

Prior research in people with type 1 diabetes also suggests that, at the time of the diagnosis, they feel that HCPs are more concerned about glucose levels than about their emotional well-being (24). Therefore, giving diagnoses of diabetes requires HCPs to be aware of the multiple factors at play, including patients' age and understanding, their family's understanding and support, and societal illness attribution and potential blame and stigma. Considering our findings in the context of prior literature, providing additional psychological support immediately after diagnosis may be necessary to help people mentally adjust to their condition and mitigate the risk of future psychosocial issues. In addition, equipping HCPs with strategies to communicate and empathize with their patients can improve diagnostic delivery methods and aid in the development of more effective coping mechanisms.

Our findings also demonstrate that participants with type 2 diabetes expressed greater concern about long-term complications at diagnosis than did their counterparts with type 1 diabetes. This finding may be attributed to the older age at diagnosis of participants with type 2 diabetes, which may contribute to heightened awareness of health risks associated with the condition. Existing research indicates that perceived risk of complications and negative views toward illnesses are associated with an overall decrease in well-being (32,33). However, some studies have shown that interventions led by HCPs can aid people in developing a more optimistic perception of their illness (34). These findings emphasize the importance of HCPs acknowledging and addressing fears about complications, while also providing sufficient resources to enable people to avoid complications. Moreover, implementing interventions that focus on improving

individuals' views and attitudes toward their illness could also prove beneficial to their overall mental health.

Surprise was another significant component of the diagnosis experience. Most participants with type 1 diabetes expressed feelings of shock or surprise at the time of their diagnosis. This finding may be explained by their younger age at diagnosis or the fact that many of them led healthy lifestyles not commonly associated with diabetes. For many of these participants, accepting their diagnosis was difficult, and many described feeling a sense of denial in the beginning. Previous research has shown that reluctance to accept a diabetes diagnosis is associated with decreased self-care behaviors, higher A1C, higher diabetes distress scores, and more depressive symptoms (35). HCP training aimed at helping people accept their diagnosis may improve their diabetes self-management and overall well-being. Conversely, participants with type 2 diabetes did not express surprise with their diagnosis. Most of them reported having prediabetes and/or a family history of diabetes, so they expected their diagnosis of type 2 diabetes; unfortunately, this expectation may be associated with feelings of being blamed and consequent feelings of stigma for having caused their diabetes (36). Understanding similarities and differences in diagnosis experiences is important so that HCPs can tailor how they deliver diagnoses and support to the unique needs of individuals.

Limitations

Study limitations include the homogeneity of the sample with regard to race and geographical location. The predominantly White study sample does not reflect the racial distribution of the world; however, it is representative of southeastern Ohio (37). Similarly, we collected data from one geographical region, and the experiences expressed by these participants may not be transferable to people around the globe. For this reason, future mixed-methods research should examine type 1 and type 2 diabetes diagnosis stories from multiple geographical regions.

Additional study limitations include selection bias and social desirability bias. With regard to selection bias, participants who volunteered for interviews may have experienced more emotional reactions to their diabetes diagnosis than did people who did not volunteer to participate. Self-reported qualitative data also are vulnerable to social desirability bias. To minimize bias, we informed all participants that their responses were confidential and could not be linked back to their personal identity.

Finally, the analysis for this article was centered around the first few interview questions. Future research should focus solely on diagnosis experiences and examine links between those experiences and self-management behaviors over time. Furthermore, our findings warrant additional research that examines diabetes diagnosis stories as they relate to coping styles and psychosocial issues such as diabetes distress and depressive symptoms.

Conclusion

Findings from this qualitative study reveal the emotional impact of a diabetes diagnosis among people with either type 1 or type 2 diabetes. Most participants expressed similar emotional reactions of fear, sadness, confusion, and worry when diagnosed with diabetes. Differences between participants with type 1 diabetes and those with type 2 diabetes included that participants with type 2 diabetes were more likely to have expected their diagnosis and to express concerns about long-term complications, which may affect their later psychosocial adjustment. However, participants with type 1 diabetes reported feeling shocked and surprised by their diagnosis.

HCPs deliver thousands of diabetes diagnoses over the course of their clinical practice; however, individuals are diagnosed with diabetes only once. How HCPs deliver diagnoses may be crucial to individuals' acceptance of the condition and their coping strategies. HCPs should consider assessing people's emotional reactions to their diagnosis, which may help to identify people at high risk for low diabetes acceptance and long-term psychosocial issues. Longitudinal research with a larger, more diverse sample is needed to test this hypothesis.

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AUTHOR CONTRIBUTIONS

All authors contributed to the study conception, design, and analysis; interpreting data; writing and revising the manuscript; and approving the manuscript for submission. E.A.B.

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.

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