

# Reasons for Open and Closed Attitudes Regarding Type 1 Diabetes

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## ■ ABSTRACT

Thirty-one adults with type 1 diabetes participated in this qualitative study to explore reasons why they were willing (had an open attitude) or unwilling (had a closed attitude) to disclose diabetes-related information to others. Participants (61.3% female, mean age 38.48 years, mean duration of diabetes 21.94 years, 100% white) answered open-ended questions about living with type 1 diabetes. Interviews were transcribed verbatim and coded to identify major patterns that emerged in the data. Reasons for open attitudes included support from others, confidence and feeling comfortable, feeling normal despite diabetes, seeking to educate, and feeling that it was not a major concern to share information with others. Reasons for closed attitudes included fear of discrimination, misunderstanding from others, embarrassment and shame, and feeling that it was not a major concern to share information. A higher number of participants reported open attitudes after diagnosis than at initial diagnosis; a lower number of participants reported closed attitudes after diagnosis than at initial diagnosis. Professionals should consider effective forms of type 1 diabetes-related education to reduce diabetes misconceptions and discrimination against diagnosed individuals. This may help individuals feel more open and willing to adhere to and seek assistance with their diabetes-related self-care.

Nearly 1.25 million American children and adults have been diagnosed with type 1 diabetes, an autoimmune disease that destroys pancreatic  $\beta$ -cells and stops the body's natural production of insulin (1). Because insulin is an essential hormone that regulates blood glucose (2), lifelong insulin therapy, glycemic management, and frequent visits to medical specialists are important to avoid ketoacidosis, heart disease, kidney disease, and blindness (3). Despite short-term consequences (e.g., dizziness and confusion) and severe long-term consequences (e.g., retinopathy and renal disease) (4), many individuals still have difficulty adhering to their diabetes regimen. An individual's attitude regarding type 1 diabetes may be related to his

or her approach to diabetes management (e.g., a closed or reserved attitude may lead to avoiding taking insulin in public, which could pose potential health risks). This study explored adults' perceptions of and reasons for willingness (having an open attitude) or unwillingness (having a closed attitude) to disclose diabetes-related information to others.

An open attitude may be defined as an individual's willingness to disclose diabetes-related information. Individuals who are open may be more willing to talk about their diabetes and test their glucose levels or administer insulin shots in front of others rather than trying to hide their disease. No research has investigated specific reasons for openness regarding type 1 diabetes, but some

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studies have shown its benefits. Many of these studies have focused on children and adolescents.

For example, research has shown that when adolescents communicate with their parents about diabetes-related issues, the parents have more knowledge regarding management needs (5), and there is more parental involvement in and monitoring of diabetes management tasks (5,6). For adolescents, parental involvement, communication, and supervision are positively associated with adherence to the diabetes regimen (7–9). Openness about diabetes may also reduce depressive symptoms in individuals with type 1 diabetes (5). In addition, an open attitude may be beneficial for students in academic settings. Research has shown that when students are open about type 1 diabetes, teachers are less likely to attribute classroom problems to health factors rather than to nonconformity or defiant behavior (10) and may be more accommodating to student needs (11).

Individuals with a closed attitude may feel less inclined to disclose information regarding their diabetes. They may be secretive and may avoid performing management tasks in public or even taking insulin altogether. The literature examining closed attitudes largely focuses on children and adolescents. Studies show that adolescents tend to be more secretive and closed about diabetes-related issues because of anticipated disapproval and punishment from parents (12), shame and self-blame for diabetes (6), low parental warmth (13), fear of negative peer and friend reactions (14), and negative feedback from teachers (15).

Closed attitudes may lead to poorer glycemic control (13), higher A1C levels (5), poorer adherence to the diabetes regimen, higher depression levels (13), less self-control (16), and more conduct problems in adolescents (13). Constant efforts to maintain secrecy may lead to emotional and physical burdens (16), as well as missed opportunities for sup-

port offered by others (14). Burdens and lack of support may increase stress and difficulty coping.

Although a large number of individuals with type 1 diabetes are diagnosed young and begin to learn to cope during childhood and adolescence, managing diabetes is a lifelong experience. During emerging adulthood, when young people with type 1 diabetes are transitioning to independence and adult medical care, emerging adults often engage in suboptimal self-care behaviors and experience out-of-range glycemic control and poor continuity of medical care (17). An open attitude in discussing these experiences and issues could be beneficial.

Additionally, research shows that adults who have diabetes experience personal and psychological problems and are twice as likely to be depressed as those without diabetes (18). Depression is related to poor diabetes self-management, diabetes-related complications, hyperglycemia, and higher mortality rates (18). Researchers suggest that it is important to address the personal and psychological burdens associated with living with type 1 diabetes (18); however, the literature on psychosocial factors and challenges related to type 1 diabetes outcomes is lacking (19). Understanding reasons for openness can help promote healthy, open attitudes and behaviors throughout the life span and perhaps help diminish the psychological challenges associated with type 1 diabetes.

No studies have explored specific reasons for open attitudes, and few studies have explored reasons for closed attitudes. Understanding reasons for openness may help professionals promote this attitude and its associated benefits, and understanding and responding appropriately to reasons for closed attitudes may help break down adherence barriers. Because most type 1 diabetes studies have focused primarily on children and adolescents, there is a gap in the research on adults. The purpose of

this study was to add to the limited research that identifies some reasons behind open and closed attitudes surrounding diabetes, as well as the potential health consequences of those attitudes, specifically filling the gap in adult-focused studies.

## Methods

### Sample

Thirty-one participants were recruited through purposive and snowball sampling. Flyers were distributed by a diabetes clinic, and participants were also recruited by word of mouth. Participants were asked to nominate other individuals they knew who were  $\geq 18$  years of age and had type 1 diabetes to participate. Most participants were diagnosed as children or adolescents (before the age of 20 years); however, we recruited some individuals ( $n = 7$ ) who had been diagnosed as adults to achieve maximum variation in age at diagnosis (20). Participants ranged in age from 20 to 70 years (mean 38.48, SD 16.73). Age at diagnosis ranged from 2 to 48 years (mean 16.39, SD 9.66), and individuals had lived with diabetes on average for 21.94 years (SD 13.55). Nineteen participants (61.3%) were female. At the time of the interviews, 25 participants (80.6%) used insulin pumps. Participants were white, middle class, and residents of a western state.

### Procedure and Measures

The majority of participants (96.8%) completed two interviews, each lasting 1 hour on average. Participants were interviewed by trained research assistants in locations convenient to them or by telephone, if preferred. In the first interview, participants responded to the general prompt, "Tell me about growing up and living with type 1 diabetes." Participants guided this interview, except when asked to explain further or go into greater detail. Participants were interviewed again  $\sim 1$  week later to obtain any needed clarification on statements from the first interview and to answer

TABLE 1. Participants' Reports on Open Attitudes at Their Initial Diagnosis and After Diagnosis\*

Reasons for an Open Attitude	Participants Who Reported Theme at Diagnosis (n)	Participants Who Reported Theme After Diagnosis (n)	Participants Who Reported Open Attitudes Toward:	Number of Times Theme Was Reported at Diagnosis	Number of Times Theme Was Reported After Diagnosis	Sample Quotations
Support. Participants felt others were supportive, nonjudgmental, understanding, and willing to help with type 1 diabetes. Participants may have sought help regarding management or type 1 diabetes-related issues.	6	10	Family (children, siblings, parents, grandparents, aunts/uncles, cousins, etc.) Spouse Peers (friends, coworkers, community, neighbors, church members, or general) Romantic partners (including spouse before they were married) Nonmedical professionals (teachers, coaches, principals, bosses, etc.)	0 1 6 0 1	3 2 15 2 1	"I was pretty open about it . . . I remember going to . . . lunch in middle school and taking insulin . . . in front of all my friends and I remember all of my friends . . . thinking it was so cool, so um . . . so I would say for the most part people were pretty accepting of it . . ." (at diagnosis) "Especially with my room-mates now . . . I tell them I'm a diabetic . . . if this happens, then you need to do this . . ." (after diagnosis) "I don't mind talking about [diabetes] . . . to my wife or to my family, people who honestly care, because it's such a personal part of me . . ." (after diagnosis)

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more specific prompts (e.g., "Tell us about when you were diagnosed with type 1 diabetes" and "Tell us about how you self-manage your diabetes").

### Data Management and Analysis

All interviews were recorded with digital audio recorders, transcribed verbatim, and uploaded into NVivo qualitative data analysis software version 10 (QSR International, Doncaster, Australia) for data organization and management. Researchers used an inductive approach to data coding. Initially, two researchers independently read each interview and used a process of open coding to identify major patterns that emerged in the data (20,21). If differences in coding occurred, they were resolved through discussion with a third researcher. In the axial coding phase of the analysis, two additional researchers collapsed some categories and also identified subcategories, focusing on the open and closed attitude categories for the purpose of this study (20,21). Throughout the analysis, researchers revised category and subcategory descriptions and produced an audit trail to document the emerging themes.

After the final categories and subcategories were confirmed, researchers identified participant quotations that best illustrated the subcategories. The two initial researchers and the third researcher then discussed and finalized the categories, subcategories, and most representative quotations.

### Results

A core category emerging in the data analysis of the interview transcripts was participants' attitudes toward type 1 diabetes. Two major themes emerged from the data: open attitudes and closed attitudes. Individuals discussed their open and closed attitudes toward caregivers (i.e., parents or spouse), family members, peers, romantic partners, and nonmedical professionals (e.g., teachers, coaches, principals, or bosses).

TABLE 1. Participants' Reports on Open Attitudes at Their Initial Diagnosis and After Diagnosis\*, continued from p. 39

Reasons for an Open Attitude	Participants Who Reported Theme at Diagnosis (n)	Participants Who Reported Theme After Diagnosis (n)	Participants Who Reported Open Attitudes Toward:	Number of Times Theme Was Reported at Diagnosis	Number of Times Theme Was Reported After Diagnosis	Sample Quotations
Confident and comfortable. Participants were not embarrassed by their diagnosis, or they did not care about others' judgments. They may have perceived type 1 diabetes as a positive, distinguishing feature.	4	9	Peers Romantic partners	3 1	15 1	"It didn't really bother me that much and in . . . some weird way I almost liked it because the attention that I got . . . at school . . ." (at diagnosis) "I'm not embarrassed anymore . . . They ask about my pump. I show it to them. They ask about my site. I show them with all the scarring . . . There's no reason to be embarrassed." (after diagnosis)
Viewed self as normal. Participants did not feel defined by type 1 diabetes (i.e., they viewed themselves as normal despite having type 1 diabetes).	2	5	Peers	2	5	"Everybody knew I had it . . . I never tried to hide it . . . I always tried to prove that I could do anything anybody else could do." (at diagnosis) "I started wearing my pump outside . . . I felt like it was part of the ownership process . . . just making it something that I had and something that was a part of me, but that didn't define me." (after diagnosis)
Education. Participants wanted to help others understand type 1 diabetes and management, or to avoid confusion about type 1 diabetes and management.	1	4	Peers	1	4	"I was constantly trying to explain it to school friends . . . They all didn't really understand that they couldn't catch it . . . It made me feel awful that they thought it was contagious somehow." (at diagnosis) "I just tried to be open and honest about it so that there wasn't speculation or confusion about what was going on." (after diagnosis)

TABLE CONTINUED ON P. 41 →

TABLE 1. Participants' Reports on Open Attitudes at Their Initial Diagnosis and After Diagnosis\*, continued from p. 40

Reasons for an Open Attitude	Participants Who Reported Theme at Diagnosis (n)	Participants Who Reported Theme After Diagnosis (n)	Participants Who Reported Open Attitudes Toward:	Number of Times Theme Was Reported at Diagnosis	Number of Times Theme Was Reported After Diagnosis	Sample Quotations
"Not a big deal." Participants did not think it was a big deal to tell/show people or not tell/show people about type 1 diabetes and management.	1	9	Family	0	1	"I think the second half of my mission I pretty much didn't care. I'm like, 'Yeah, I've got diabetes.'" (at diagnosis)
			Peers	1	5	
Unspecified. Participants did not give reasons why they were open about type 1 diabetes.	0	1	Romantic partners	1	4	"My wife didn't know I was diabetic until . . . we were on a date . . . and I just pulled out my stuff, like it's not a big deal." (after diagnosis)
			Nonmedical professionals	0	1	
			Peers	0	1	"I just do [insulin in public] wherever." (after diagnosis)

\*Includes reports from 11 participants for at diagnosis and 22 participants for after diagnosis. Some participants may have reported under multiple subcategories.

### Reasons for Open Attitudes

An open attitude referred to a participant's willingness to share or talk about type 1 diabetes. Participants showed an open attitude as a result of 1) supportive behaviors demonstrated by others, 2) feeling confident and comfortable about diabetes, 3) desiring to feel normal despite diabetes, 4) seeking to inform others about type 1 diabetes and its management, or 5) a casual attitude. Analysis of transcripts also showed that participants demonstrated open attitudes both at initial diagnosis (defined as typically occurring up to 1 year after diagnosis) and after diagnosis (defined as typically occurring >1 year after diagnosis) (Table 1).

Support was the most commonly reported reason why participants expressed openness toward others about type 1 diabetes. When others were nonjudgmental, understanding, and willing to help, participants were more open. A 25-year-old man diagnosed at the age of 19 years stated, "I don't mind talking about [diabetes] . . . to my wife or to my family, people who honestly care . . ." The number of participants who described support as a reason for an open attitude was lower at diagnosis ( $n = 6$ ) than after diagnosis ( $n = 10$ ).

Some participants demonstrated openness towards peers and romantic partners because they were not embarrassed and did not care about others' judgments. We labeled this category "confident and comfortable." A 59-year-old woman diagnosed at the age of 19 years stated that she had "never been embarrassed by the diabetes . . . [and that it] has [n]ever affected any relationships . . ." For some, type 1 diabetes was a positive, distinguishing feature of themselves. A 60-year-old woman diagnosed at the age of 16 years expressed how she was "not embarrassed anymore," but that her diabetes made her feel unique and that she stood out from others. A greater number of these participants expressed being open after

TABLE 2. Participants' Reports on Closed Attitudes at Their Initial Diagnosis and After Diagnosis\*

Reasons for a Closed Attitude	Participants Who Reported Theme at Diagnosis (n)	Participants Who Reported Theme After Diagnosis (n)	Participants Who Reported Closed Attitudes Toward:	Number of Times Theme Was Reported at Diagnosis	Number of Times Theme Was Reported After Diagnosis	Sample Quotations
Discrimination. Participants feared being discriminated against or treated/viewed differently because of type 1 diabetes. They wanted to be viewed as normal (i.e., not defined by type 1 diabetes).	7	10	Family	0	1	"I feel like my coaches ... didn't dare push me like other kids on the team because they knew I was diabetic. They treated me a little different ... It made me feel different ... It made me mad ... I didn't do anything where I would have to eat candy or interact ... I wasn't telling anybody. It was a big secret." (at diagnosis)
			Peers	14	19	
Embarrassment and shame. Participants were embarrassed by or felt ashamed about having type 1 diabetes. They did not want to draw attention to themselves or to type 1 diabetes.	6	2	Romantic partners	0	1	"I think [being private] helped me because, like I said, I didn't want to be treated differently ... " (after diagnosis)
			Nonmedical Professionals	2	0	
	6	2	Peers	8	0	"I was so embarrassed ... I tried to hide that if I forgot [an injection], I wouldn't say anything to anybody. I would just go the day without it." (at diagnosis)
			Nonmedical professionals	0	2	
Misunderstanding. Participants felt others did not understand type 1 diabetes (e.g., the difference between type 1 and type 2 diabetes or how diabetes is managed).	4	6	Family	0	1	"In the beginning, I'm often too shy to really explain [type 1 diabetes], so I'd rather just sit through a meeting with low blood sugars and have the side effects ... " (after diagnosis)
			Peers	4	6	
	4	6	Nonmedical professionals	1	1	"When I first got it ... [I] was dropping urine into water and shaking a pill ... I wouldn't do that at school ... I didn't want people seeing me do that ... It's like, 'They're gonna think I'm doing drugs.'" (at diagnosis)
			Family	0	1	
			Peers	4	6	"A lot of times I wait forever until I'm out of public situations and then I take care of [low blood sugars] ... If everybody was more educated ... I might be more comfortable saying 'Hey, my blood sugar's low, it's not a big deal ... '" (after diagnosis)

TABLE CONTINUED ON P. 43 →

TABLE 2. Participants' Reports on Closed Attitudes at Their Initial Diagnosis and After Diagnosis\*, continued from p. 42

Reasons for a Closed Attitude	Participants Who Reported Theme at Diagnosis (n)	Participants Who Reported Theme After Diagnosis (n)	Participants Who Reported Closed Attitudes Toward:	Number of Times Theme Was Reported at Diagnosis	Number of Times Theme Was Reported After Diagnosis	Sample Quotations
"Not a big deal." Participants did not feel the need to tell people about type 1 diabetes or management.	3	3	Peers Romantic partners Nonmedical professionals	1 1 1	2 1 1	"Well, some of the coworkers want to mother you about it, but I pretty much blow that kind of thing off. I'll say, 'Don't worry about it. If I need your help, I'll ask for it.'" (at diagnosis) "I don't tell most of my professors in college 'cause I just don't find it relevant . . ." (after diagnosis)
Unspecified. Participants did not give reasons why they were closed about type 1 diabetes.	3	4	Parents Family Peers Romantic partners	1 0 3 0	0 1 1 2	"I kept it private. Even from my parents . . . my mom . . . she knew very little about diabetes even after I'd had it . . . I guess I just went about my life doing it, but I was very private about it." (at diagnosis) "When I was dating . . . sometimes I'd hide . . . I would take my shot . . . in the restroom or something and then come out to eat . . ." (after diagnosis)

\*Includes reports from a total of 13 participants for at diagnosis and 11 participants for after diagnosis. Some participants may have reported under multiple subcategories.

diagnosis ( $n = 9$ ) than at their initial diagnosis ( $n = 4$ ), perhaps as a benefit of adjustment over time.

Participants who did not feel defined by their diabetes, but rather viewed themselves as normal despite their diagnosis, were more open toward their peers. A 20-year-old woman diagnosed at the age of 5 years realized that diabetes "was a part of [her], but . . . didn't define [her]" and said that visibly wearing her pump endorsed her ownership of her diagnosis. Slightly more participants in this category expressed openness after diagnosis ( $n = 5$ ) than at initial diagnosis ( $n = 2$ ).

Some participants were open with peers to educate them and help them more accurately understand diabetes management (e.g., diet, exercise, and stress-induced blood glucose levels), as well as the differences between type 1 and type 2 diabetes. Perhaps participants felt that people were generally ignorant of type 1 diabetes and "that more awareness [needed] to be brought to [it]," as one 30-year-old woman diagnosed at 9 years of age said. There was a slightly higher number of participants who reported openness because they wanted to educate others after diagnosis ( $n = 4$ ) than at initial diagnosis ( $n = 1$ ).

Participants also reported openness toward others because they were indifferent to sharing (i.e., thought their diabetes was "no big deal"). A 38-year-old man diagnosed at the age of 19 years said that "after a while [he] . . . didn't really care" that people knew he had diabetes. Believing that diabetes was no big deal was more commonly reported after diagnosis ( $n = 9$ ) than at diagnosis ( $n = 1$ ).

In summary, there were fewer reports of being open at initial diagnosis ( $n = 14$ ) than after diagnosis ( $n = 38$ ). Participants showed open attitudes primarily because they sought support from others, thought their diabetes was no big deal, and felt confident and comfortable with their diagnosis.

### Reasons for Closed Attitudes

Individuals exhibited a closed attitude when they were reserved or secretive about type 1 diabetes either at or after diagnosis. Participants showed a closed attitude because of 1) fear of discrimination, 2) misunderstanding about type 1 diabetes, 3) embarrassment and shame regarding diabetes, or 4) a feeling that their diabetes was no big deal (Table 2).

The most common reason participants reported being closed toward peers, nonmedical professionals, family members, and romantic partners was fear of discrimination (i.e., fear that others would treat or view them differently). Participants expressed a desire to be viewed as normal. A 64-year-old woman diagnosed at the age of 10 years said, "Nobody will know because I want to be normal." More participants reported being closed because of discrimination after diagnosis ( $n = 10$ ) than at initial diagnosis ( $n = 7$ ).

Participants also showed a closed attitude because they felt embarrassed and ashamed about their diagnosis. Participants reported a fear of "having reactions in public because . . . [of] draw[ing] . . . attention to [themselves] . . ." Individuals also sometimes felt embarrassed or ashamed because they blamed themselves for having diabetes. A 64-year-old woman diagnosed at the age of 19 years said the reason she was private when she was first diagnosed was because of "shame . . . [and] a little . . . guilt . . ." and questioned "would [she] have not gotten [diagnosed] if [she] had not been secretly on birth control pills?" Fewer numbers of participants had closed attitudes due to embarrassment or shame after diagnosis ( $n = 2$ ) than at initial diagnosis ( $n = 6$ ), suggesting that participants may become comfortable with type 1 diabetes over time. Both at and after the time of initial diagnosis, participants' embarrassment and shame led to closed behaviors predominately toward peers. For example, one 30-year-old

woman diagnosed at the age of 10 years recounted that "most of [her] friends . . . [didn't know] . . . until after high school . . ."

Feelings of embarrassment about their diagnosis may lead to maladaptive adherence behaviors for some people with type 1 diabetes. A 60-year-old woman diagnosed at the age of 16 years said she felt "so embarrassed" to administer shots in public that "if I forgot [an injection], I wouldn't say anything . . . I would just go the day without it."

Some participants were closed toward others because they felt that others did not understand or were not educated about type 1 diabetes (e.g., differences between type 1 and type 2 or how diabetes is managed). A 30-year-old man diagnosed at the age of 9 years demonstrated closed attitudes because "of the stereotype of being overweight . . . [and having] to explain to people that [type 2 diabetes] is the one that is normally caused by lifestyle habits and choices . . ." He said he "got . . . tired of . . . being different." Slightly more participants reported being closed because of misunderstanding after diagnosis ( $n = 6$ ) than at the initial diagnosis ( $n = 4$ ).

Participants reported closed attitudes toward peers, romantic partners, and nonmedical professionals because they did not feel the need to discuss their diabetes (i.e., it was "no big deal"). A 22-year-old female diagnosed at the age of 16 years said, "I don't tell most of my professors in college 'cause I just don't find it relevant . . ." The number of participants who reported being closed for this reason were the same both at and after diagnosis ( $n = 3$ ). Although some participants felt that it was no big deal to be open about their diagnosis, others felt that disclosure was unnecessary.

Overall, there were slightly fewer reports of reasons for being closed at initial diagnosis ( $n = 23$ ) than after diagnosis ( $n = 25$ ). However, within some subcategories, more participants reported being closed after compared

to at their initial diagnosis. Whereas a greater number of participants reported showing closed attitudes because of discrimination and misunderstanding after diagnosis, slightly fewer participants reported feeling embarrassed and ashamed after diagnosis.

Results also showed that some participants consistently exhibited open or closed attitudes both at diagnosis and after diagnosis, whereas others fluctuated in their attitudes. Eleven participants reported only open attitudes at or after diagnosis or for both. In contrast, four participants reported only closed attitudes at or after diagnosis or for both. Twelve participants reported a combination of open and closed attitudes at or after diagnosis or for both.

### Discussion

In analyzing interviews of adults who had lived with type 1 diabetes, a core category of participants' attitudes toward diabetes emerged. Participants described open and closed attitudes toward their diabetes both at and after diagnosis. They also described a number of reasons for their open and closed attitudes.

The most common reason participants exhibited open attitudes was because of support from others. Individuals may be open so that they can have additional support to cope with type 1 diabetes and its management. Research shows that positive support from health care providers, spouses, and family members may help to reduce diabetes-related distress (22), improve blood glucose testing (23), and improve diabetes coping skills (24). Nurse educators, doctors, and therapists should continue to educate caregivers, romantic partners, and nonmedical professionals about how to positively support those with type 1 diabetes. Encouraging support may contribute to individuals feeling more comfortable disclosing information and seeking assistance in their diabetes-related self-care.



Feeling confident and comfortable also allowed participants to be open about their diabetes. Such feelings may be a result of developing resilient traits that help with the challenges of living with a chronic illness. One study found that lower levels of resiliency were associated with higher levels of distress, maladaptive coping strategies, poorer quality of life, and poorer glycemic control in adolescents with type 1 diabetes (25). Little research has investigated feelings of confidence versus shame when living with a chronic illness. Future research might consider what resources may reduce shame and increase confidence in those with type 1 diabetes and also explore sex differences with regard to these feelings.

Findings also suggest that as participants adjusted, they may have accepted that diabetes was a component of themselves but did not limit their capabilities or potential to lead a normal life. Believing this may have led participants to feel less embarrassed and more confident and comfortable and thereby to share more openly with others.

Participants also did not want others to limit or define them by type 1 diabetes. If participants felt limited by others because of their diabetes from the time they were first diagnosed, they may have chosen to remain closed to avoid any further discrimination. Research with emerging adults shows that young women aged 18–24 years share similar fears of being defined by their diagnosis instead of being seen or treated as normal (26).

Although more participants showed open attitudes after diagnosis, many still exhibited closed attitudes because of discrimination. This may be partially the result of people's lack of understanding about type 1 diabetes. Some evidence suggests that as discrimination and stigmatization increase, a person's willingness to share or seek help regarding disability decreases (27). Little research has explored this relationship with regard

to type 1 diabetes. Future research should investigate people's beliefs regarding a person's control over type 1 diabetes, how these beliefs influence the way they treat those with the diagnosis, and how their treatment might influence an individual's own beliefs about his or her diabetes. Understanding these matters may discourage blaming people with type 1 diabetes for their disease and reduce the fear of people with the disease about carrying out their self-care tasks in public situations.

Research with adults indicates that the emotional burden of living with type 1 diabetes is associated with higher levels of depression and lower quality of life (28). Helping those with type 1 diabetes avoid embarrassment could help to reduce their emotional burden and consequently improve their regimen adherence and health outcomes.

Interestingly, for the themes of discrimination, misunderstanding, and embarrassment and shame, participants overwhelmingly reported peers as the people toward whom they had closed attitudes. In contrast, peers were also the individuals from whom participants felt the most support; participants revealed that they were open because they felt confident and comfortable with peers. These results point to the importance of the peer group for individuals with type 1 diabetes. Innovative approaches are needed for working with the peers of adolescents, emerging adults, and adults with type 1 diabetes. Diabetes educators and medical social workers will need to be creative in developing ways to educate peers about the realities of type 1 diabetes and about how they can support their friends with type 1 diabetes.

Some participants in our study ( $n = 11$ ) only exhibited open attitudes, some only showed closed attitudes ( $n = 4$ ), and others expressed both open and closed attitudes ( $n = 12$ ). For this reason, health care providers and family members should be cognizant of the possibility that diagnosed

individuals may be ambivalent in their attitudes, while at the same time working to eliminate factors that might contribute to closed attitudes.

Several limitations of this research should be considered. The sample was homogeneous with regard to race and socioeconomic status. In addition, participants ranged in age from 20 to 70 years, and those who were older or who had a longer duration of diabetes may not have remembered their experiences at diagnosis as well as did younger participants. In addition, because participants were asked to recall past experiences, it is possible that recall bias affected their responses. Time and adjustment may influence how people recall perceiving their initial experience with diagnosis. Future research should continue to investigate open and closed attitudes using more diverse samples. In addition, future research could compare open and closed attitudes in individuals who have been recently diagnosed to those who have lived with type 1 diabetes for a longer period of time.

## Conclusion

The majority of type 1 diabetes research has centered on children and adolescents. This study aimed to bridge the gap by interviewing adults with type 1 diabetes to explore reasons behind their open and closed attitudes surrounding diabetes. The most commonly reported reason for openness was that participants sought support from those who were nonjudgmental, understanding, and willing to help. The most commonly reported reason for showing closed attitudes was fear of discrimination. Researchers found fewer participants with closed attitudes and more participants with open attitudes after diagnosis compared to at the initial diagnosis.

Health care professionals should consider effective forms of type 1 diabetes education and ways to expand its scope to reach more people. Such efforts could reduce misconceptions

and encourage people to engage in more positive support. This in turn may help individuals with type 1 diabetes feel more open and willing to seek assistance with their diabetes self-care.

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### Duality of Interest

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

### Author Contributions

J.K.E., H.M.H., and S.O.R. wrote the manuscript. All of the authors researched the data, contributed to the discussion, and reviewed and edited the manuscript. S.O.R. is the guarantor of this work and, as such, had full access to all of 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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