



Patient Decision-Making About Self-Disclosure of a Type 2 Diabetes Diagnosis: A Qualitative Study

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BACKGROUND | Effective self-management of type 2 diabetes requires receiving support, which can result from disclosing the diagnosis to a support network, including coworkers, family, and friends. As a primarily invisible disease, diabetes allows people to choose whether to disclose. This study qualitatively explores the factors that influence a person's decision to disclose diabetes to others.

METHODS | Research coordinators recruited 22 interview participants, ranging in age from 32 to 64 years, whose medical records included a diagnosis code for type 2 diabetes. Participants received care from one of two U.S. medical centers. Semi-structured interviews lasted approximately 1 hour and were audio-recorded and professionally transcribed. Verification strategies such as memo-keeping and maintaining methodological coherence/congruence were used throughout analysis to promote rigor.

RESULTS | In patients' descriptions of their decision-making processes regarding whether to disclose their diagnosis, six themes emerged. Three motivations prompted open disclosure: 1) to seek information, 2) to seek social support, and 3) to end the succession of diabetes, and the other three motivations prompted guarded disclosure: 4) to prepare for an emergency, 5) to maintain an image of health, and 6) to protect employment.

CONCLUSION | Based on our findings, we recommend three communicative actions for clinicians as they talk to patients about a diabetes diagnosis. First, clinicians should talk about the benefits of disclosure. Second, they should directly address stereotypes in an effort to de-stigmatize diabetes. Finally, clinicians can teach the skills of disclosure. As disclosure efficacy increases, a person's likelihood to disclose also increases. Individuals can use communication as a tool to gain the knowledge and support they need for diabetes self-management and to interrupt the continuing multi-generational development of diabetes within their family.

Management of type 2 diabetes requires extensive self-care, including glucose monitoring, making nutritional choices, getting regular physical activity, and attending routine medical appointments (1). Effective self-management requires receiving both practical and social support, which may only result from disclosing the diagnosis to members of a support network that includes coworkers, family, and friends (2,3). Within families, although disclosure of diabetes-related worries and distress is a strong predictor of spousal support (4), studies document that between 53 and 65% of people living with type 2 diabetes talk about their diabetes with their relatives (5–7). Disclosure is the act of revealing information, and self-disclosure refers to the act of telling another person a

piece of information (8). This study focuses on the act of telling another person about one's personal disease status. This act is different from disclosure as discussed in some medical and nursing literature, which conceptualizes disclosure as an "act of seeking care," referring to the sharing of information specifically with a health care professional or clinician (9).

More frequently studied among young adults living with type 1 diabetes, diabetes disclosure is a strategy to engage in helpful social relationships (10,11). Young adults disclose their type 1 diabetes diagnosis in anticipation of the need for practical and emotional support and with the desire to normalize type 1 diabetes (12). Adolescents and young adults

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living with type 1 diabetes describe three disclosure strategies: open disclosure, in which individuals directly share their diabetes diagnosis and readily request diabetes-related support; disclosure hesitancy, in which individuals reluctantly disclose their diagnosis or actively hide it; and passive disclosure, in which individuals allow health-significant others such as parents to disclose the diagnosis or they disclose through the display of self-management tasks such as checking blood glucose openly so that others observe the behavior (13).

As a primarily invisible disease, diabetes allows individuals to choose whether to disclose (14). Nondisclosure may negatively affect self-management (e.g., by leading to adverse eating patterns or delayed glucose monitoring) and may decrease the opportunity for receiving critical assistance from others such as during emergency hypoglycemia situations (15). Previous research suggests three specific barriers to disclosure. First, individuals may perceive disease as private, personal information (16). Second, individuals may be part of a culture in which talking about disease is taboo (17). Third, across cultures, individuals may perceive a stigma associated with type 2 diabetes, which prompts selective disclosure of a diagnosis (18–20). As the prevalence of diabetes has continued to rise, perceived shame and stigma surrounding the diagnosis has also increased (21–23). Studies involving African Americans living with diabetes have demonstrated that diabetes was not discussed in the family; authors linked this lack of communication to perceptions of stigma attached to diabetes within families and the community (20,24). In the Appalachian community, individuals wrestle with the idea of disclosure, voicing the need to tell others for health and safety reasons, but also anticipating potential feelings of embarrassment and judgment by others (16). In the Korean immigrant community, individuals living with type 2 diabetes often do not disclose the diagnosis within or outside the family in an effort to maintain an image of being healthy (25). This stigma also exists in Korea, where self-stigma prompts avoiding disclosure (26).

This study qualitatively explored the factors that influence individuals’ decisions to disclose their diabetes diagnoses to others. By developing an understanding of how people choose to disclose or to not disclose their disease status to others, clinicians and other health care professionals may be able to tailor their counseling to encourage planned disclosure that can build patients’ social support networks.

Research Design and Methods

After Institutional Review Board approval, participants were recruited from a larger federally funded mixed-methods study designed to develop a physician curriculum on diabetes care (27). Our goal was to examine a diverse range of cases

that were relevant to the type 2 diabetes diagnosis process. Purposive sampling was used with maximum variation, and data collection continued until saturation was achieved. Using a respondent pool from a patient survey that was part of the larger study, researchers invited all survey respondents ($N = 773$) (28) through a mailed invitation. Research coordinators recruited 22 interview participants. As participants volunteered, they were scheduled for interviews.

Participants received care from one of two medical centers in distinct regions of the United States. One medical center was in Augusta, GA, in the southeast, a geographic region with a high prevalence of diabetes (29). The other medical center was in Las Vegas, NV, in the western region, which has a comparatively lower prevalence of diabetes.

Participants ranged in age from 32 to 64 years, and all had a diagnosis code for type 2 diabetes in their electronic medical record. Interviewees’ demographic data are summarized in Table 1.

The first author (C.J.W.L.) created the interview guide for the larger study in collaboration with another qualitative research expert. Table 2 provides example questions from the interview guide. C.J.W.L. instructed two research assistants on the use of the interview guide before data collection. Research coordinators obtained consent and demographic data. The two research assistants and C.J.W.L. collected data from October 2016 to April 2017. Semi-structured interviews lasted approximately 1 hour each and were audio-recorded and professionally transcribed, resulting in more than 1,239 pages of data. To decrease participant burden and maintain privacy, interviews were conducted at participants’ primary care centers.

TABLE 1 Interview Sample Characteristics ($n = 22$)

Characteristic	Value
Race/ethnicity	
White American	10 (45.5)
Black or African American	7 (31.8)
Asian American (including Filipino)	3 (13.6)
Hispanic American	1 (4.5)
Mixed race	1 (4.5)
Sex	
Male	13 (51.5)
Female	9 (48.5)
Treatment modality	
Oral medication	15 (68.2)
Oral and insulin	5 (22.7)
None	2 (9.1)
Age, years	56.32 (32–64)
Diabetes duration, years	9.65 (2–25)

Data are n (%) or mean (range).

TABLE 2 Example Questions from the Interview Guide

- Tell me about the first time your provider talked to you about diabetes.
- What do you think caused your diabetes?
- How do you experience diabetes? How does diabetes feel to you?
- How does diabetes impact your life?
- Tell me about the types of meals your family eats together.
 - When together as a family, do you or other family members eat differently?
 - How does your family respond to your eating differently?
- Tell me about times you share meals with friends.
- Tell me about how you fit physical activity into your life.
 - Does your family exercise with you?
- Does your family talk about your diabetes?
 - How do you describe your diabetes to your children?
 - What kinds of questions do your children ask you about your diabetes?

Because this was a secondary analysis, the analytic process was not done concurrently with data collection; rather it was completed once all data had been collected (30,31). In phase 1 of the analysis, a qualitative expert (L.A.C.) instructed a medical student (C.V.) on the iterative process of qualitative analysis. They were not involved in the data collection. The two researchers (L.A.C. and C.V.) met multiple times over a period of 6 months to become immersed in the data and discuss participant descriptions of disclosure. Researchers then identified and segmented data that reflected these constructs by analyzing half of the interview transcripts to conduct a preliminary thematic analysis and identify potential themes derived from the data. Data analysis was managed and coded through the use of Microsoft Excel software and handwritten field notes. In phase 2, C.J.W.L. joined the analysis process. The three researchers (L.A.C., C.V., and C.J.W.L.) sought to validate emerging themes by reviewing the analysis conducted on the segmented text while also conducting axial coding to define each theme's characteristics and confirm data saturation. In phase 3 of analysis, a fourth researcher (E.W.W.) used the finalized codebook to reanalyze all interviews to ensure all four of Guba and Lincoln's criteria (32) were met. Verification strategies such as memo-keeping and maintaining methodological coherence/congruence were used throughout analysis to promote rigor (33).

Results

In participants' descriptions of the decision-making processes that informed their decisions regarding whether to disclose their diagnosis, six themes emerged. Three motivations prompted open disclosure: 1) to seek information, 2) to seek social support, and 3) to end the succession

of diabetes. The other three motivations prompted guarded disclosure: 4) to prepare for an emergency, 5) to maintain an image of health, and 6) to protect employment.

The first three motivations prompted open disclosure, whereas motivations 4, 5, and 6 prompted guarded disclosure. These themes are described below using quotes from participants' narratives.

Themes Prompting Open Disclosure

Theme 1: Seeking Information

Participants openly disclosed their diabetes diagnosis when they wanted to hear information from other people who were living with type 2 diabetes. As one patient said, "It's kind of like, if you're a smoker, you know all the people that smoke. You're a diabetic, you hear other people that have it, so then you kind of talk to them a little bit . . . I talk to people because, in talking to them, sometimes I might find out things that I don't know about" (Patient 14, male). Another patient described a similar tactic in the workplace:

"I don't try to pry on their [co-workers'] health, and I don't ask them, but . . . if they volunteer it, I will question it and try to get more information . . . [O]ne of my coworkers, he's about my height, he weighs about 25 pounds heavier than me, and he's trying to tell me to watch what I eat" (Patient 3, male).

Theme 2: Seeking Social Support

Within this group, participants generally disclosed to others with whom they experience everyday living. As one patient described it, "My best friend, he has the same thing I got. Exact. He takes the same exact medicine I take, and we have two different doctors . . . [A]t least three or four times a month, he's at my house, or I'm at his house, but, yeah, we talk about that. We were both kind of diagnosed at the same time" (Patient 11, male).

Participants said that sharing the diagnosis was often connected to social eating situations. They described situations in which they told others about their diagnosis, hoping that others would support their healthy eating behavior. As one patient said, "You have to let them know that's got too many calories, it's too sweet, I can't eat it . . . I'm working on this diabetic thing, trying to get my A1C level down" (Patient 8, female). This was also true in working environments in which coworkers saw each other's lunches. One participant said, "We talk every day, and we talk about food" (Patient 15, female).

Disclosure was common among couples, which prompted spousal support. One patient noted that she and her

husband both had diabetes, which enabled them to encourage each other in healthy choices. “Every once in a while, we try to encourage one another,” she said. “We’ll see each other making a poor choice, and we’ll say something like, you know, ‘Maybe we should do something else.’ Or, ‘After this, you know, this is it. We’re not gonna do this anymore’” (Patient 13, female). Another patient received her diagnosis while she was dating her current husband. She said, “He knew about it right away, just because, like, we were always together, you know, so it’s important to have somebody to confide in” (Patient 22, female).

Theme 3: Ending the Succession of Diabetes

Participants reported telling their biological children about their diabetes diagnosis in an effort to end the succession of diabetes in the family. These participants recognized the genetic nature of type 2 diabetes. As one participant explained, “I tell my son every day, ‘You better do something now’” (Patient 13, female). Parents emphasized that they were using their own diagnosis as a warning to their children. One father said, “My son, he knows. I tell him . . . ‘[W]atch what you eat. What you eat now as a young person will bite you later on as an old person. So, watch what you’re eating now, you know? I mean it’s okay to have a hamburger now and then from outside, but not too much, you know?’” (Patient 5, male).

Another participant talked about how the visual nature of her daily treatment reminds her children about her diagnosis. She said, “He sees that sometimes Mommy pokes herself in the morning. And, you know, this little thing . . . he loves my little machine, and he’s always after it. He knows that Mommy takes a lot of pills, and he knows that when I’m on the insulin, he sees me with the needles and injection” (Patient 22, female). She emphasized the need to talk to her son about it in more detail when he’s older because of his genetic risk. “At some point, for his own safety, that’s gonna be discussed, but also for him to understand, you know, that it is a possibility. God willing, it won’t be until like, you know, he’s 60 or 70 or 100” (Patient 22, female).

Themes Prompting Guarded Disclosure

Theme 4: Preparing for an Emergency

Some participants described a need, rather than a desire, to tell others about their diabetes diagnosis, in preparation for an emergency. As one patient shared:

“After about a year, I told [my professional group] that I was diabetic, because I hear about people that are diabetic,

like eating the wrong thing and going into seizures or whatever. I thought, ‘Man, if I ever had to go to the hospital, you know, somebody should probably know that I’m diabetic,’ so I’ve told them” (Patient 7, male).

Theme 5: Maintaining an Image of Health

Some participants expressed being guarded with the disclosure of their diabetes because they wanted to maintain an outward image of health. Some even avoided talking about the disease at all. Underlying this motivation were both cultural and societal factors. One patient described his own culture’s norms regarding talking about health, saying, “Black folks don’t do that . . . We don’t communicate like that. We are more secretive about our health” (Patient 6, male). Another patient described a reticence to talk about health at all, saying, “We don’t talk. I’m very uncomfortable to talk with them, and it’s not good. I don’t want to talk to them” (Patient 17, female).

Participants also described the social stigma that surrounds diabetes in America. As one participant put it, “For a long time, I didn’t tell anybody because I was embarrassed because I did something wrong to be a diabetic. So, I didn’t really tell people” (Patient 22, female). When she did share her diagnosis, she said she regretted it:

“The few times I have shared my condition with [co-workers], people don’t understand it. They either take things way too far, or the other thing I really hate is the jokes about it. Like people will make a joke like—I think the last time this happened was at a lunch or something, and the younger guys are sitting there—like, ‘Oh, we’re gonna eat this dessert,’ and ‘Oh my God, this is like a diabetes dream’ and all this stuff” (Patient 22, female).

One participant said that, although she and her husband talk about her diagnosis, she does not talk to her children about the details of her diabetes. “They know I’m diabetic,” she said. “I guess I’m a little embarrassed about it, a little bit ashamed of it. Definitely. Because, like I said, I know I did it to myself. We don’t talk about it . . . I don’t talk about my diet or my medicine or, you know, my exercise or anything like that” (Patient 12, female).

Theme 6: Protecting Employment

The final motivation involved participants being guarded about disclosing their diagnosis to protect their employment. One patient described seeing how disclosed diagnoses have affected other employees, saying, “Everybody I know that’s had diabetes in the [workplace] that I’ve been able to open up to, every single one of them has [left the

workplace]. No one's been able to retire, so it's scary. It's seen as a negative" (Patient 22, female).

Discussion

When participants perceived benefits of disclosure such as gaining information, finding social support, or ending the succession of diabetes in their family, they openly disclosed their type 2 diabetes diagnosis to others. However, participants were guarded in their disclosure when they perceived the disease as a threat to their image or job. Participants were also guarded when they perceived that the sole benefit of disclosure was to prepare for an emergency. By understanding patients' decisions to disclose or not to disclose their disease to others, clinicians can adjust their counseling to encourage disclosure to help build a support network.

Three motivations found here echo previous studies that describe a disclosure dialectic in which the competing value of health being personal is weighed against the need to tell others to get help (16). Participants said they knew they needed help, whether in the form of information, support, or aid in the event of an emergency. Our results also replicate a previous finding that participants worry about the career implications of a diabetes diagnosis (19). This work-related barrier to disclosure has also been connected to other health conditions such as concussion (34,35).

Our findings can be interpreted within the framework of the disclosure decision-making model (DD-MM) (36). The DD-MM explicates the process of a patient's decision to enact a disclosure event based on three assessments: 1) five qualities of the diagnosis itself: perceived stigma, prognosis, symptoms, expectation of the diagnosis, and relevance of the diagnosis to others; 2) the quality of the relationship with and anticipated reaction of the receiver of the disclosure; and 3) the patient's perceived skills and confidence to share the information (disclosure efficacy). The emerging themes in our study align with the qualities of the diagnosis.

Participants did not talk about the symptoms of diabetes, such as increased thirst and fatigue, but rather focused on the behavior changes that a diabetes diagnosis requires, such as reducing carbohydrate intake and increasing physical activity. Behavior changes were visual cues that something in the patient's life had changed or that the patient was different from the group. These visible behavior changes provided opportunities for participants to disclose, rather than directly prompt a disclosure. Perceived stigma emerged as a significant barrier to disclosure.

In our sample, the hereditary nature of diabetes influenced both participants' expectations of the diagnosis and their

beliefs about the relevance of the diagnosis to others, particularly their biological children. Diabetes disclosure motivated by a desire to end the succession of diabetes within the family resonates with previous survey research showing that people who were worried about relatives' health were more likely to disclose their diagnosis and talk about the link to family risk (37). This disclosure motivation indicates that some people could be receptive to clinicians asking them to inform their relatives about familial susceptibility to type 2 diabetes and preventive options (38), similar to interventions of patient-mediated cascade screening for familial hypercholesterolemia (39). Research shows that adult children of individuals living with type 2 diabetes are open to receiving information from family members about reducing their own risk of developing type 2 diabetes (40,41).

This study builds on previous literature that identified the disclosure decision-making process for young adults living with type 1 diabetes (10–13). With a focus on how patients diagnosed with type 2 diabetes make disclosure decisions, this study extends previous literature that revealed barriers to disclosure for patients living with type 2 diabetes (18–22,24) to identify the decision-making process for disclosing their disease to others. It also confirms patterns of disclosure decisions revealed among specific cultural groups (16,23,25). This study can be used to inform intervention development to promote disclosure with patients receiving a type 2 diabetes diagnosis. Future research should investigate the downstream effects of interventions on patient self-management behavior and glyce-mic control.

Our qualitative findings do not replicate previous work that demonstrated a sex/gender difference in which women more readily disclosed the diagnosis to friends and family (42). The study here was not designed as a comparative qualitative study, but our data revealed that both men and women choose both open and guarded disclosure. Similarly, we do not reveal differences among participants from different cultural groups. Although culture influenced perceptions of disease, it did not do so uniformly. Rather than make generic recommendations, we suggest that clinicians tailor their communication to individual patients (43).

Clinical Implications

Based on our findings, we recommend three specific communicative actions for clinicians as they talk to patients about a new or existing diabetes diagnosis. First, clinicians should talk to patients about the benefits of disclosure. Patients may not inherently know or understand the benefits of gathering information, gaining social support, and sharing information of future risk with the family. Clinicians can introduce this

idea within the SPIKES framework (44), which provides steps for delivering bad or life-altering news such as a chronic diagnosis. Although the SPIKES framework does not directly address disclosure, it includes two points for introducing disclosure and social support in the conversation. When considering the setting, clinicians should consider who is present in the encounter and ask the patient if there is anyone else whom the patient wants to have join them in the conversation. Then, when summarizing the strategy and next steps, the clinician can ask questions about the patient's social network, particularly listening for the size and diversity (i.e., blend of family and friends) of the patient's social network (45). Clinicians should encourage patients to disclose their diagnosis to a mix of friends, family, and colleagues who can provide social support in the different situations and settings that a patient living with diabetes will encounter (46). If a patient is initially hesitant to disclose the diagnosis to others, providers can ask open-ended questions, discuss the person's worries and concerns, listen, and be empathic and sympathetic (47). Providers should not confront patients or push back if they are hesitant, but rather reframe the recommendation to disclose the diagnosis and help patients identify benefits and drawbacks of disclosure.

Second, clinicians can teach patients the skills of disclosure. Overall, this type of skill-building may not fit into the initial diagnosis appointment and may require longitudinal patient education concerning social support. Patients can develop disclosure efficacy through preparation and rehearsal (48). When patients plan and practice disclosure, potentially within the structure of diabetes education classes and groups, they can develop confidence and reduce uncertainty in disclosure conversations (49). As disclosure efficacy increases, patients' likelihood to disclose increases (36). One immediate tactic that clinicians can enact to increase disclosure efficacy is decreasing the perceived stigma associated with the diagnosis (50).

Third, clinicians should directly address stereotypes in the clinic in an effort to de-stigmatize diabetes. Our results, along with other studies (18,19,26,51), have demonstrated how the perceived stigma of diabetes can inhibit patient self-management. When clinicians candidly discuss existing stereotypes in clinical conversations with patients, they take a first step toward addressing stigmas. Within the SPIKES framework (44), as clinicians assess the patient's knowledge about diabetes, they can actively listen for potential stereotypes that they should address and potentially correct.

Limitations

The limitations of this study include a relatively low number of participants, although the main themes reached saturation,

which suggests that enough participants were enrolled. Recall and social desirability bias are also inherent in the use of interviews. Finally, in this population, all participants had health insurance and equitable access to care, which is not consistent in many groups.

Conclusion

Individuals living with diabetes vary in how they disclose their diagnosis to family members and others in their social support network. When individuals perceive benefits to disclosure, they openly disclose their diagnosis and open opportunities for others to support them in self-management strategies. Clinicians can positively motivate patients to disclose their diabetes diagnosis by increasing their disclosure efficacy.

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DUALITY OF INTEREST

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

AUTHOR CONTRIBUTIONS

C.J.W.L. contributed to the study design, data analysis, and manuscript writing. C.V. and E.W.W. assisted with data analysis. L.A.C. contributed to data analysis, logistics, and manuscript writing. J.T.J. contributed to writing and editing the manuscript. D.A.S. contributed to the manuscript and assisted in the study design. C.J.W.L. 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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