



Remodeling Type 2 Diabetes Diagnosis: What Individuals Need for Success

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The diagnosis of type 2 diabetes initiates a new health-illness transition. However, little is known about the immediate support that people need to successfully cope with this diagnosis. This qualitative study explored the experiences and immediate support needed at the point of diagnosis among individuals with type 2 diabetes. The findings suggest the need for health care professionals to render immediate emotional support in the form of reassurance and partnership to manage the condition together. Pre- and post-counseling sessions can minimize the emotional and psychological strain associated with the new diagnosis. Individuals should be given information on available resources, as well as an immediate connection with a health care partner who can provide guidance and help with the transition.

Diabetes is a rapidly growing and serious chronic condition of concern in every country. In the United States, ~1.4 million new cases of diabetes are diagnosed each year, and there are currently 37.3 million people living with diabetes (1). Diabetes can lead to several deleterious complications, posing significant problems to individuals, national health care systems, and economies. In the United States alone, the overall cost associated with managing care for people with diagnosed diabetes increased by 26% over a 5-year period, rising from \$245 billion in 2012 to \$327 billion in 2017 (2). Type 2 diabetes is the most common form of diabetes, accounting for 90–95% of all cases (3).

As with the diagnosis of other chronic conditions, the diagnosis of type 2 diabetes has been documented to be a difficult and stressful life event (4). Individuals newly diagnosed with type 2 diabetes need support, as not following through with recommended treatment and self-management of the condition can lead to poor health outcomes (5). Diabetes self-management education and support (DSMES) is the

gold standard service for people living with diabetes (6). Yet, only 7% of individuals newly diagnosed with diabetes in the United States utilize this essential service (7,8), potentially resulting in individuals not meeting glycemic targets and ultimately developing complications.

At the time of type 2 diabetes diagnosis, individuals often experience a health-illness transition through which they move from a state of perceived wellness to learning they have a chronic condition (9). Transition is described as the “passage from one life phase, condition, or status to another” (10,11) with periods of vulnerability to health-related risks/dangers with the shift from health to illness (11). When this transition is not properly managed, it can result in serious negative consequences for individuals, their well-being, and their health outcomes (12).

Although people with diabetes have the highest rate of health care utilization in the United States (13), it is largely unknown how they experience this health-illness transition at the time of diagnosis and how to enhance this process for adults. It is crucial for health care professionals (HCPs) to understand the immediate support needs of individuals at the point of diagnosis and to know which early support measures will help individuals move from a stressful life event to being ready to live with and cope with the condition (14). This study was based on Meleis’ Transitions Theory, which is useful to identify and interpret factors that may prevent people from becoming empowered or activated to effectively cope with a condition that requires learning and mastering of new skills (15).

Only through the description and understanding of the lived experiences of individuals who have navigated this transition can we know exactly what inhibits or facilitates healthy transition at the time of type 2 diabetes

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diagnosis (16,17). This study explored the experiences of people newly diagnosed with type 2 diabetes to learn about the immediate support they perceived they needed at diagnosis to set them up for successful transition to living with and managing the disease.

Design and Methods

A qualitative phenomenological research design (18) was used to obtain a rich description of the experiences and immediate support needs of adults diagnosed with type 2 diabetes across the United States.

Sampling Method and Sample Size

A purposeful sampling technique was used to recruit participants diagnosed with type 2 diabetes within the previous 12 months. A sample size of 25 participants was estimated (19), but data saturation was deemed to have been reached after interviewing 24 participants.

Research Participants

Recruitment for the study included ResearchMatch, a national health volunteer registry that was created by several academic institutions and supported by the U.S. National Institutes of Health as part of the Clinical Translational Science Award program. ResearchMatch has a large population of volunteers who have consented to be contacted by researchers about health studies for which they may be eligible. Review and approval for this study and all procedures was obtained from The Pennsylvania State University institutional review board. All study participants who eventually took part in the study were from ResearchMatch and Studyfinder, the university's research recruitment site.

Inclusion criteria were individuals residing in the United States who were diagnosed with type 2 diabetes within the previous 12 months, of any gender and race or ethnicity, willing and able to participate in either a synchronous or asynchronous online focus group or individual interview in English, and between the ages of 18 and 64 years. This age limit was used because of the American Diabetes Association's recommendation of different treatment guidelines for older adults and pediatric patients (20,21).

Procedures

Online focus groups (synchronous and asynchronous) and individual interviews were the two main data collection methods. Both methods were used to ensure geographically diverse participants and flexibility to enable people from different U.S. time zones to participate in the study (22).

The focus groups and individual interviews were conducted by M.D.S.B. from August to December 2021. Eligible participants had the option to choose between any of the data collection methods. Participants were assigned to a focus group based on their availability and preferences until a group size of about five participants for the asynchronous focus groups (22) and six to eight for the synchronous groups was reached. The focus groups were not constructed based on any specific criteria because the study topic did not warrant any special groupings to ensure that individuals were comfortable to describe their experiences (23). Ten participants were individually interviewed for an in-depth discussion after conducting three online focus groups.

Study Instrument

A semistructured focus guide was developed by M.B.S.B. using the concepts in the Transitions Theory (9). The guide was approved by coauthors who are experts in diabetes and qualitative studies. The same guide was used to moderate the individual interviews because the questions did not require group decision on any point.

Data Collection

Participants were sent a Google form to provide their demographic information to further ensure that only eligible participants were included in the study. Individuals were reminded at the beginning of the focus groups and interviews to engage in the discussion, avoid interrupting anyone during the discussion, and keep all information discussed confidential. M.D.S.B. moderated all of the focus groups and interviews. The synchronous focus groups and the individual interviews were conducted via Zoom and were audio-recorded with participants' consent. All of the synchronous online focus groups lasted for 120 minutes, and the individual interviews lasted between 45 and 60 minutes.

One asynchronous online focus group was conducted on a private Facebook page created specifically for this study, and the discussion lasted for 7 days to give individuals sufficient time to reflect and comment on posts at their convenience. Four participants used their Facebook account name to participate on the Facebook page. Only one participant decided to remain anonymous and used a different name approved by M.D.S.B. Before the start of the discussion on the first day, participants were informed about general rules of posting only content relevant to the study and being polite when commenting on others' posts. At least three main questions in the focus guide were posted each day on the group page. Follow-up questions

were posted beneath participants' comments for their response. All posts were reviewed and approved by the moderator. All of the posts and comments on the page were manually copied and pasted into a Word document. After this, the group page was closed, and participants could no longer access the page. The long duration of the focus groups and the individual interviews was intended to enhance the quality and credibility of the study findings (24).

The audio-recordings of the synchronous online focus groups and individual interviews were transcribed verbatim by professional transcribers and audited by M.D.S.B. Transcripts of the focus groups were shared with study participants to ensure that the transcript captured details of the various discussions. Only 10 participants responded with additional comments within the 2-week period during which they could provide feedback. Participants who participated in the online focus groups were compensated with \$40 for their time, and those who were individually interviewed received \$20.

Data Analysis

Study transcripts were uploaded into MAXQDA (VERBI Software) to aid with analysis. Data were analyzed using an inductive thematic approach (25). Six stages of thematic analysis were followed: 1) familiarization with the data, 2) generation of initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, and 6) writing the report. All of the transcripts were read, and codes were inductively identified to create a codebook during the second reading. The codes were grouped into themes and subthemes. Codes and themes identified by M.D.S.B. were discussed with the coauthors in five separate meetings and modified based on these discussions to reflect the quotes captured under each theme.

Results

The data collection sources are displayed in Table 1.

Participant Characteristics

The demographic characteristics of the study participants ($N = 24$) are presented in Table 2. The recruitment process resulted in a demographically diverse sample from 18 states in the United States. A total of 14 females (58%) and 10 males (42%) between the ages of 25 and 60 years took part in the study. The majority ($n = 19$, 79%) had at least a 4-year college degree, and only 21% were referred for diabetes education after diagnosis.

TABLE 1 Source of Data

Participants ($N = 24$)	n (%)
Focus group 1	5 (20.8)
Focus group 2	4 (16.7)
Facebook chat	5 (20.8)
Individual interviews	10 (41.7)
Total	24 (100)

Qualitative Themes

Four themes, each with several subthemes that describe the experiences and support needs of the participants, emerged from the qualitative analysis of the data (Table 3).

Theme 1: Unexpected Versus Anticipated Type 2 Diabetes Health-Illness Transition

Participants were asked how they discovered that they had type 2 diabetes, and they described their experience in various ways. The two main pathways to diagnosis identified were: 1) presenting to a health care facility with another illness or symptoms of diabetes and 2) through a routine physical/health examination.

TABLE 2 Demographic Information of Participants

Variables	n (%)
Age, years	
18-30	6 (25)
31-40	3 (12.5)
41-50	3 (12.5)
51-60	12 (50)
Sex	
Female	14 (58.3)
Male	10 (41.7)
Race/ethnicity	
African American/Black	10 (41.7)
White	14 (58.3)
Non-Hispanics	24 (100)
Hispanics	0 (0)
Education level	
High school	2 (8.3)
Associate's degree	1 (4.2)
Some college	2 (8.3)
4-year college degree/Bachelor's degree	11 (45.8)
Post-baccalaureate/Master's degree/doctorate	8 (33.3)
Referral for diabetes education	
Yes	5 (20.8)
No	19 (79.2)

TABLE 3 Qualitative Themes and Subthemes

Theme	Subthemes
1. Unexpected versus anticipated type 2 diabetes health-illness transition	A. Unexpected diagnosis B. Anticipated diagnosis
2. Strong emotions and unexpressed concerns	A. Strong emotional reaction B. Psychological reaction
3. Lack of patient engagement and partnership	A. Medically focused, unilateral conversations B. Limited opportunity to express concerns at diagnosis C. Unclear lifestyle management information shared at diagnosis
4. Comprehensive, team-based diabetes support was needed	A. Immediate reassurance from HCPs and counselors was needed B. Provide informational materials on available resources C. Provide immediate connection with a health care partner D. Referral for ongoing education and support

Subtheme 1A: Unexpected Diagnosis

Most of the participants, especially those younger than 45 years of age, did not perceive themselves as being at risk for diabetes and indicated they were unexpectedly told they had type 2 diabetes after laboratory investigations for either health complaints or a routine physical examination (Table 4). Nearly all participants, including those with a history of prediabetes, who reported not feeling well said they became aware that they had been having symptoms of diabetes only after diagnosis.

Subtheme 1B: Anticipated Diagnosis

Most of the participants who were diagnosed through a regular physical examination had a history of other chronic conditions such as prediabetes, gestational diabetes, or high cholesterol levels. These individuals were aware of their risk of developing type 2 diabetes and had regular checkups with their HCPs. Many of these participants said they were taking measures to avoid receiving

the diagnosis. Although some participants were aware of their risk, the diagnosis was still unexpected (Table 4).

Theme 2: Strong Emotions and Unexpressed Concerns

Strong emotions and unexpressed concerns were common at the time of diagnosis. These were further divided into two subthemes to reflect the emotional and psychological reactions to the diagnosis.

Subtheme 2A: Strong Emotional Reaction

A common experience reported by all the participants was the feeling of strong emotions irrespective of their perceived risk of the diagnosis. Figure 1 is a summary of participants' pathways to diagnosis and emotional reactions to diagnosis. Individuals not expecting the diagnosis experienced a wide range of negative emotions such as denial, shock, anger, and sadness compared with those who knew they were at risk for developing diabetes. Denial and shock were common among participants <45 years

TABLE 4 Unexpected Versus Anticipated Health-Illness Transition

Subtheme	Representative Quotes
Unexpected diagnosis	<p>"I actually just went to a regular doctor's appointment. I wasn't feeling good . . . My doctor went ahead and did blood work . . . She told me [that I have diabetes]. That's how I found out." (35-year-old White female, focus group 1)</p> <p>"I had an annual physical [examination], and she [the doctor] wanted me to do blood work just to check everything. And then it came back that my A1C and my glucose were high." (53-year-old White female, individual interview)</p>
Anticipated diagnosis	<p>"I knew it was coming because I routinely saw my primary care doctor, and I had been prediabetic for at least 2 years. I was aware of my A1C slowly increasing." (52-year-old White male, individual interview)</p> <p>"I had gestational diabetes when I was pregnant with both my sons, so I knew that raised my risk. Even with nutritional support and exercise the last 20 years, my blood sugars have been higher than what they should be." (51-year-old White female, Facebook group)</p>

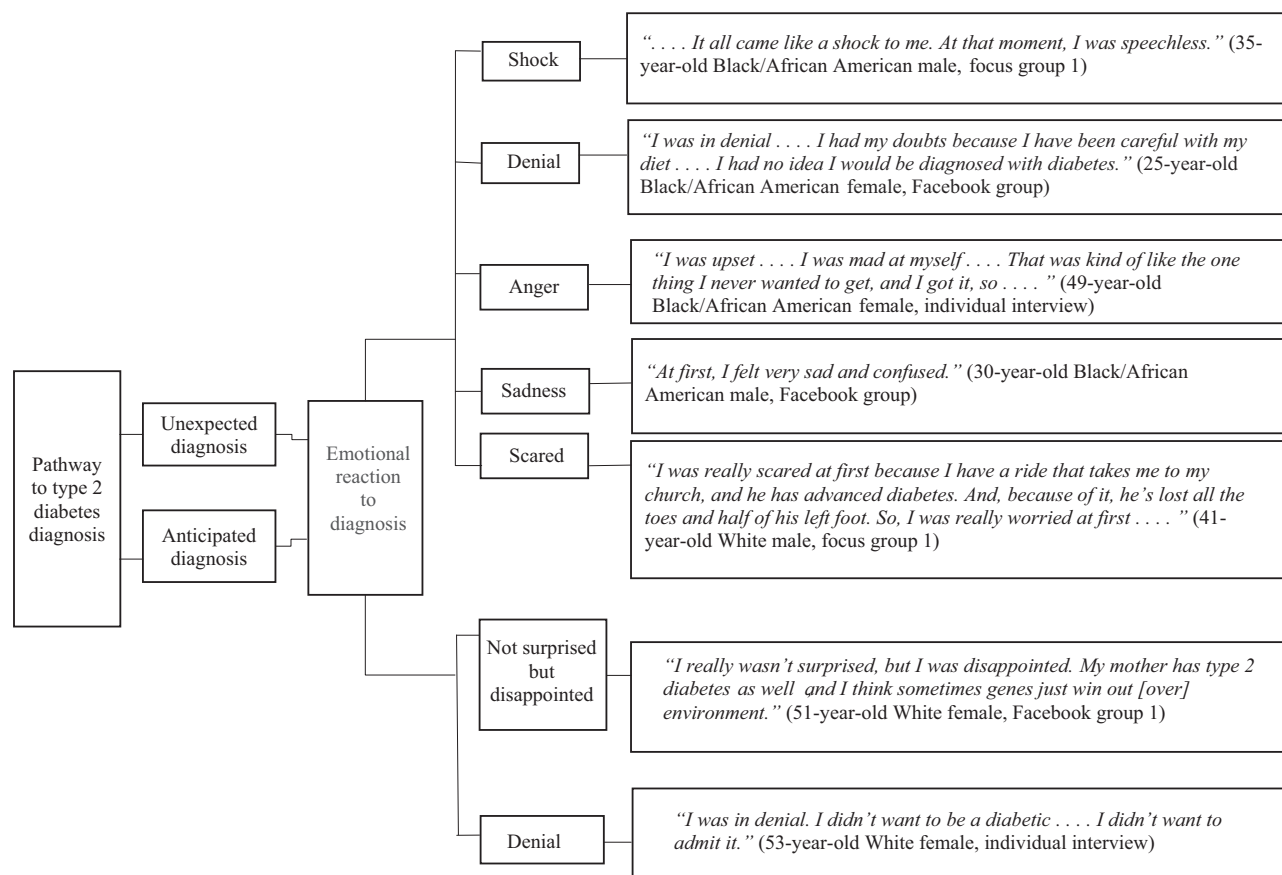


FIGURE 1 Differences in emotional reaction to the type 2 diabetes diagnosis among study participants.

of age because they perceived themselves as having no risk for the condition. Most of the participants with a history of prediabetes reported not being surprised by the diagnosis, yet shared that they felt disappointed.

For some, receiving the diagnosis added to their other comorbid conditions, which frightened them and made them sad. Some participants with prediabetes said they were angry about the diagnosis because they felt let down by their care team for not putting stringent measures in place to prevent the diagnosis.

Subtheme 2B: Psychological Reactions

Participants described their psychological reactions in terms of thoughts about what led to their diagnosis, how they will manage the condition, and what the short- and long-term impacts of type 2 diabetes may be (Table 5).

Self-blame for the diagnosis

Many of the participants were curious about what caused them to develop diabetes. Almost all said they analyzed their lifestyle and tried to figure out if it had

led to the diagnosis. Participants who expected the diagnosis blamed themselves the most for having the condition and attributed the cause to unhealthy lifestyle choices. Some participants said they were aware of the contributing effects of both genetics and lifestyle on the development of type 2 diabetes. However, even among those participants, the majority still blamed the diagnosis on their unhealthy lifestyle.

Grieving impending lifestyle changes and diabetes medication

Participants indicated that they were distressed over perceived lifestyle changes and impending requirements for diabetes medication. Often, they said they knew others living with diabetes and, because of this exposure, knew that their lifestyle needed to change. For some participants, not being able to eat particular foods was a major issue, and they were unsure about how they were going to cope. In addition to the thoughts about the impending changes, many dreaded the necessary attention and effort they would need to dedicate to effectively manage the condition. A participant who was surprised by the diagnosis shared these thoughts:

TABLE 5 Psychological Reaction to Type 2 Diabetes Diagnosis

Reaction	Representative Quotes
Self-blame for diagnosis	<i>"I have known it was a possibility for many years. I have tried to keep it from happening, but genes won out over my determination."</i> (51-year-old White female, Facebook group)
Grieving impending lifestyle changes and diabetes medication	<i>". . . When you hear diabetes, you think, 'Oh, I'm never going to get cake again. I'm never going to get ice cream again . . . At that time, I felt like I had to make a choice, and it was really disheartening in a lot of ways."</i> (51-year-old White female, individual interview) <i>"I thought I would have to take the insulin and I would have to be sticking myself with needles, and that was something that I did not want to do . . . That was based upon what I have seen with other people in my life that have diabetes. Those were the things that were going through my mind."</i> (53-year-old Black/African American male, individual interview)
Fear of diabetes stigma and complications	<i>". . . in my own case, the problem I had then [at diagnosis] was . . . my fear of the feelings my friends and people around me would show toward me [as a result of the diagnosis]."</i> (35-year-old White male, focus group 2) <i>". . . the first thing that came to my mind was kidney failure, because I know people that have diabetes, and they have kidney problems."</i> (53-year-old Black/African American male, individual interview)

". . . initially, I was like, 'Oh, crap. Here's something to deal with. Here's something else to try to figure out,' . . . because, even though there are doctors, and they help take care of you, really, it's your responsibility to take care of yourself." (58-year-old White female, individual interview)

Most participants had family members and friends living with diabetes and recognized diabetes as a lifelong condition. They were concerned about taking medication for the rest of their life. Participants >45 years of age were worried about having to take insulin. Some were also concerned about regular blood glucose monitoring because of fears about using needles. Some participants incorrectly believed that using insulin was an indication of advanced diabetes and therefore something to be avoided.

Fear of diabetes stigma and complications

The idea of being stigmatized because of diabetes was a prominent issue among individuals <45 years of age. One of the study's youngest participants, who previously believed diabetes only affects older adults, described his greatest concern after learning he had the condition:

"I feared the stigma . . . I'm 27 years old, and I'm married with a kid. And, imagine a 27-year-old man having diabetes . . . It's appalling, seriously . . . So, that was my experience." (27-year-old Black/African American male, focus group 1)

Participants who were <40 years of age feared being judged by friends and family if they adjusted their lifestyle because of the diagnosis. Most participants were concerned that others would blame them for having developed diabetes.

In addition to fears about stigma, concerns about potential diabetes complications were also common. Participants were aware of the negative effects diabetes could have on the body when the condition is not managed well. The most common complications participants were concerned with were kidney disease, amputation, and heart disease.

Although younger participants (<45 years of age) thought of type 2 diabetes at the time of diagnosis as a life-threatening condition because of its potential complications, older participants felt that their health had already deteriorated with the diagnosis and that they would encounter lifelong difficulties.

Theme 3: Lack of Patient Engagement and Partnership
Subtheme 3A: Medically Focused, Unilateral Conversations

The conversation individuals had with their HCPs at diagnosis was typically described as unilateral, with HCPs instructing them on how to manage their diabetes (i.e., taking medication and making lifestyle changes). A participant shared her experience about the nature of the conversation at diagnosis:

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“I was told [about the management]. I wasn’t involved. [The doctor said] ‘This is how it’s done . . . This is the standard protocol. We wait 3 months. You try and do this, that, and we will watch your numbers.’ There was nothing like, ‘Let’s talk about what would work for you. How do you prefer to learn?’ No one said, ‘Hey, how about we start with a dietitian right away. Maybe that will help you get this under control, and you’ll have help’ . . . No, nothing. It was, ‘You go away [and] do your thing’” (55-year-old White female, individual interview)

Subtheme 3B: Limited Opportunity to Express Concerns at Diagnosis

Although participants were concerned about the negative consequences of diagnosis on their life, the majority did not share the impact the diagnosis had on them with their HCPs. The conversation at diagnosis, led by HCPs, centered on the medical aspects of the condition. HCPs did not ask about their concerns, worries, or preferences. The strong emotional reactions experienced at diagnosis left some participants stunned and speechless, making it difficult for them to be active participants in their care.

Because the diagnosis was often unexpected and difficult to process, participants shared they did not know what they needed or what questions to ask because of their inadequate knowledge and the shock of the diagnosis. Other participants mentioned that they knew their HCPs were busy and only had limited appointment time for discussion. Because of these constraints, many blamed the health care system for not giving individuals sufficient time at diagnosis to interact with their HCPs and to get what they needed from the interaction.

“I think the problem we have, it’s not necessarily with the individual providers, but [with] the system as a whole When I make a doctor’s appointment, depending on what I’m having done, it’s only like 15–20 minutes That’s just the system as a whole, just kind of like, ‘Churn them and get them out of here’ So, you feel, like, intimidated. You don’t want to ask something because you know there’s somebody waiting after you.” (53-year-old White female, individual interview)

Subtheme 3C: Unclear Lifestyle Management Information Shared at Diagnosis

Participants were not satisfied with the way information about lifestyle modification was presented at diagnosis. Their role and responsibility in terms of self-managing the condition were overly simplified by some providers.

“What I clearly understood was: take your medicine and avoid processed sugars. Those were the rules, as I understood them. That was my role.” (60-year-old White male, individual interview)

Recommendations for exercise at diagnosis also lacked clarity and specificity.

“. . . it’s just kind of a general term, ‘Be more active.’” (52-year-old White male, individual interview)

Some participants felt the information at diagnosis was not personalized or detailed because the HCPs simply stated that they would refer them to see a dietitian or a diabetes care and education specialist for comprehensive self-management education.

Theme 4: Comprehensive, Team-Based Diabetes Support Was Needed

Subtheme 4A: Immediate Reassurance From HCPs and Counselors Was Needed

The majority of the participants strongly recommended immediate emotional support from HCPs because of the surge of emotions and psychological responses to the diagnosis. Reassurance of HCPs’ support was mentioned as a critical step in forming a relationship at the time of diagnosis.

“Just let people know, ‘We’re in this together. It’s not a death sentence, so we can handle this’ They have to feel like they have somebody on their side, and they’re not alone.” (49-year-old Black/African American female, individual interview)

Participants said HCPs should provide information about the various advanced treatment options available, as many individuals are not knowledgeable about current diabetes management guidelines. Because of the fear of losing the things they enjoy, participants urged HCPs to reassure individuals that lifestyle changes will still enable them to enjoy [foods they like] in moderation.

“I think just letting people know that it does require lifestyle changes, but it’s not like you cannot have your favorite things I felt like I could never have . . . the things that I enjoy ever again. And, just realizing that, as long as I managed the rest of my day, I can make room for treats every now and then [was important]. But, it is not an all-or-nothing thing.” (53-year-old White female, individual interview)

Because of the short time frame of the diagnosis appointment, participants recommended having

individuals visit a counselor or a psychologist as part of the diagnosis process to address their emotional needs. Participants endorsed having a counselor for individuals who experience denial at diagnosis, especially when the diagnosis is unexpected. There was a consensus among the participants that a referral for counseling should be a next step to ensure that individuals have support to deal with the guilt and self-blame that occurs at diagnosis. Participants also shared similar views during the individual interviews. Aside from having a counselor to talk to after diagnosis, participants suggested that counseling sessions should be part of diabetes education to destigmatize and normalize the idea of getting assistance to cope with the diagnosis.

“ . . . I suppose if the diabetes educator had, maybe, a diabetes counseling portion in it, where you didn’t think, ‘Oh, well, I need to see a counselor because I got sick,’ but sort of like, ‘Oh, let’s talk a little bit about emotional self-care that you need to do,’ I think that would be worthwhile. Because then it would just sort of normalize it.” (58-year-old White female, individual interview)

Many participants stated that HCPs should prepare individuals about the prospects of receiving a diagnosis and what may be done to manage their diabetes if that happens. They believed this strategy would help to offset some of the unpleasant feelings and surprise associated with the diagnosis. One participant shared his thoughts on counseling prior to a laboratory test:

“So, I think before they conduct the [diabetes] test, they [individuals] should just contact the psychologist . . . for counseling. So, after finishing the counseling, then I [would] now come back for the test. I think then, the results wouldn’t have depressed me so much like what I experienced then.” (35-year-old White female, focus group 2)

Subtheme 4B: Provide Informational Materials on Available Resources

There was great need for information among participants at diagnosis. Although most participants indicated that they were not mentally prepared to engage in a discussion with their HCPs at diagnosis, they still expected to receive important information and resources about the condition.

Although some received booklets on diabetes, the majority shared that they were sent home without any reading

material or information except for what was shared verbally. Participants preferred informational support in the form of reading materials and videos on the condition and its management. They said they needed something they could refer to after the diagnosis had settled in, and they were ready to take action. One participant described his expectations at diagnosis:

“Websites and pamphlets explaining what the issue is, how serious it is, how it happened to me, and places to get information on improving my condition. It seemed that it was assumed that I knew all that I needed to know about it. Doing my own research delayed me in acting on my situation.” (56-year-old White male, Facebook group)

Subtheme 4C: Provide Immediate Connection With a Health Care Partner

Participants proposed connecting individuals with someone in the health care system who is knowledgeable about type 2 diabetes to provide further guidance. There were suggestions for using already available HCPs at the care facilities to serve as available support after diagnosis. Participants used terms such as “diabetes coordinator,” “case manager,” and “diabetes advocate” for that role. One participant shared her thoughts on why she needed to connect with an HCP after diagnosis:

“There should be a [diabetes] advocate . . . system. There should be an advocate who is not going to abandon them.” (55-year-old White female, individual interview)

Others had similar perceptions about the benefits of having someone designated to assist individuals after diagnosis:

“I really don’t have a whole lot of personal support A diabetes advocate will be very profitable and positive for patients.” (41-year-old White male, focus group 1)

Subtheme 4D: Referral for Ongoing Education and Support

Participants with comorbidities stated that they anticipated that their HCPs would connect them with a team of other professionals who could help them manage their condition efficiently. A participant with kidney disease disclosed:

“I thought my doctor was going to lay out in front of me a team of other professionals to help me . . . like a dietitian,

you know, like a nephrologist, a couple [of] other people that [were] going to try and . . . give me menus and some tools . . . None of that happened.” (55-year-old White female, individual interview)

Participants strongly believed that HCPs should refer individuals for more education on the management of the condition. Among the various diabetes services provided after diagnosis, participants suggested the need to first connect with a dietitian because of the need to know what is healthy to eat to manage blood glucose. It was recommended that individuals have early referral and enrollment in diabetes self-management education classes. One participant talked about the importance of being given this referral in a timely manner:

“Having immediate access to the diabetes center and associated support groups without having to wait months to get in.” (51-year-old White female, Facebook group)

Participants also stated that the information being delivered by primary care providers was superficial. Once individuals are past their initial emotional reaction and have come to some level of acceptance, they want useful information from HCPs who understand the condition. Based on how some primary care providers communicated to individuals at diagnosis, some participants felt that their HCPs did not know as much as they should about the condition and did not project the confidence they expected in a health care partner. Some even felt that their HCPs gave limited information because of a lack of knowledge. This led others to comment that referral to an endocrinologist would lead to better health outcomes.

“I think the only thing I would change is maybe if a specialist got involved at some point. Even if it’s just as a consultation to explain more in-depth . . .” (49-year-old Black/African American female, individual interview)

Having peer support was equally important to participants, as they knew they would learn how others have lived with the condition. Participants suggested being referred to peer groups for first-hand experience from those living with the condition.

“I feel like it’s important to have a good support group with people who already have been diagnosed, and [have] passed through those denial and other stages, so that it will be like a source of motivation.” (30-year-old Black/African American female, focus group 2)

Discussion

This study explored the experiences of individuals at the point of type 2 diabetes diagnosis and the immediate support they needed to smoothly transition to living with diabetes. The main themes identified in the study were: 1) unexpected versus anticipated health-illness transition, 2) strong emotions and unexpressed concerns, 3) medically focused, unilateral conversations, and 4) the need for comprehensive, team-based diabetes support. These findings show that people often have to transition from thinking of themselves as healthy to realizing that they have diabetes, and this experience necessitates the need for tailored support as soon as a diagnosis is made. Sometimes, the experience leaves people vulnerable to poor health outcomes if diabetes is not managed appropriately. This qualitative study could contribute important knowledge needed in improving support for people at the point of type 2 diabetes diagnosis. The study’s findings can inform conversations and interventions to support individuals feeling activated and connected to the health care team as partners.

Most individuals in the study were not expecting the diagnosis, making it a life-changing moment during which they become aware of vulnerabilities in their health status (15). Participants’ emotional and psychological responses to the diagnosis were similar to what other researchers have reported (4) and reflect, to some extent, their awareness of what diabetes entails and the responsibilities that come with the diagnosis (15).

Peoples’ awareness (i.e., their perceptions, knowledge, and recognition of transition) (15) triggers grief over loss of their perception of well-being and overall health (26). Because of the impact the diagnosis can have on mental health status, quality of life, social contacts, and, consequently, the health outcomes of the individual (27), researchers recommend treating the diagnosis as a process and not as a single event (26). Individuals should not be treated as if their feelings and concerns do not matter. Rather, HCPs should facilitate the process of working toward acceptance of living with diabetes by partnering to address individuals’ immediate coping and support needs (28,29).

Research has shown that people <45 years of age have a strong emotional reaction to receiving a type 2 diabetes diagnosis. People in this age-group are typically unaware of their diabetes risk and have limited understanding of what diabetes is going to mean for their life going forward (30). People who do not have close contact with someone who has diabetes or know someone who is

a positive example of living with diabetes may not completely understand what it is like to live with diabetes. As a result, HCPs should not expect individuals to understand the impact of the condition at the time of diagnosis or to have the requisite knowledge necessary to ask the right questions during consultation. Hence, individuals should be encouraged to participate in conversations at the time of diagnosis or should be given a follow-up appointment to discuss the condition when they are ready (31).

According to Meleis' Transitions Theory, individuals' level of awareness of a transition influences their level of engagement during the transition process (9). Although participants demonstrated some level of awareness at diagnosis, it was not surprising that they shared their inability to express their concerns and emotions at the time of diagnosis. The literature shows that individuals are psychologically not ready to fully engage in consultations at diagnosis (31,32). The problem of unexpressed concerns may be compounded further if HCPs fail to recognize individuals as key players in the management of their condition, leading to a lack of engagement and partnership, as reported in the study. This factor may inhibit healthy transition and optimal health outcomes, as individuals may end up feeling unmotivated to take up the needed self-care responsibilities. Rather, a person-centered approach should be adopted at diagnosis, and the conversation should be geared toward creating a partnership through which the HCP involves the individual as a partner to work together to achieve optimal health outcomes (4). The way in which the diagnosis is delivered and the individual is supported to transition from diagnosis to acceptance can influence how a person views the condition and other related services (29).

It is advised that providers offer survival skills education at diagnosis to guide individuals in the first few weeks after diagnosis regarding what they can do to care for themselves before their appointment for comprehensive education (6). Overly general information lacking specificity and clarity is likely to impede a smooth transition to coping with the condition, as vague information can create more confusion and frustration. Hence, primary care providers should give simple and practical behavior modification recommendations at diagnosis, as well as referral to diabetes services after this appointment.

Because of the challenges participants faced at diagnosis, they advocated for urgent efforts before and shortly after diagnosis to enable a smooth transition to coping with the condition. Participants emphasized the

importance of providing emotional support for anyone newly diagnosed with type 2 diabetes. Preparation for adapting to a new diagnosis is critical, and some people recommend having a counseling session before or after diagnostic laboratory work is completed to aid with the emotional reaction (4,33). A condition such as diabetes, which can cause strong emotional reactions at diagnosis, may deserve pretest counseling like the process used for HIV testing, to gradually educate and prepare individuals to understand the implications of a potential diagnosis (4,34). Individuals should be reassured that having diabetes is not their fault, as many blamed themselves for the diagnosis. Individuals with a history of prediabetes or gestational diabetes should be encouraged to focus on self-efficacy in managing diabetes because these individuals may doubt their abilities, given their disease progression.

Although participants stated that HCPs should provide emotional support, they were unable to describe how that would be practically implemented beyond offering reassuring messages and a referral to a counselor. Participants acknowledged the brief time frame of doctors' appointments and advised that counselors should be integrated into primary care settings to better support newly diagnosed individuals. Participants strongly believed this step is critical at the point of diagnosis because the negative emotions experienced cannot be ignored, and individuals need professional assistance to overcome any shame, denial, and fear experienced at diagnosis to carry out the required self-management activities. Providing this service could be challenging for some health care systems. Hence, HCPs can use avenues such as peer support groups and online counseling opportunities to offer more reassurance.

HCPs must reassure individuals about the availability of resources and a comprehensive team that will partner with them to develop the confidence and self-efficacy they need to effectively self-manage the condition and thus avoid or delay the onset of dreaded or feared complications (35). Provision of a trusted diabetes information resource was recommended to provide support for individuals as they go home to process their diagnosis. Many wanted the information to cover an overview of the condition, available resources, and next steps, which could then serve as reference materials for guidance when individuals are ready to act.

The study further revealed that participants wanted to maintain contact with an HCP after diagnosis to optimize learning and management of the condition. The lack of adequate information, emotional support, and

connection with the primary provider could be the justification for participants' need to connect with an HCP who will attend to their concerns and needs after diagnosis. A major assumption in Meleis' Transition Theory (9) is that nurses are the main caregivers of individuals and families experiencing transitions. Hence, health care systems can train a nurse to be part of the diabetes care team to perform the role of a diabetes advocate or coordinator after diagnosis.

Although only 7% of individuals newly diagnosed with diabetes in the United States use DSMES services, national standards for DSMES (36) recommend that all individuals newly diagnosed with type 2 diabetes be referred. Similar to national rates, most of the participants in this study (79%) were not referred for diabetes education or received information insufficient to encourage their participation. Such situations can hinder a healthy transition, as individuals are burdened with the additional work of searching for the right information to successfully self-manage their condition. Individuals added that a referral to a diabetes education and support group would provide important ongoing support to help them cope with diabetes and live their life in an optimal way. Research has identified low referral as a barrier to DSMES attendance. Health care facilities can use an electronic referral system, as consistent use of such a system has been associated with improved referral rates and DSMES attendance (37). Even among those who are referred, DSMES attendance is still low (38). HCPs could leverage the confidence people have in them as experts (39) to promote the use of DSMES as a crucial service that offers needed information for diabetes self-management.

Limitations and Strengths

This study had some limitations that are important to consider when interpreting its findings. First, although the recruitment process was open to all for participation, it is possible that individuals who desired better/more support after diagnosis were the ones more willing to participate in this study. Hence, the findings may be a reflection of the needs of people with limited or no initial support. Second, individuals' retrospective responses to the questions may have been susceptible to recall bias. Moreover, because of the use of focus groups as a data collection tool, there may have been social desirability bias in the ways in which participants responded to issues. A third limitation was the fact that all participants were of higher educational backgrounds; therefore, the findings may not reflect the experiences of individuals with lower educational attainment. Finally, the study

only included English-speaking participants; hence, its results did not adequately address the needs of people from diverse backgrounds who speak other languages.

Nevertheless, a strength of the study is that it included participants from 18 states throughout the United States. Therefore, its findings may be relevant for different health care delivery systems across the country.

Implications for Practice and Research

The findings of this study have several practical implications to facilitate healthy transitions at the time of type 2 diabetes diagnosis, including:

- Participants identified a need for HCPs to address patients' emotional and psychological needs at diagnosis by offering reassurance, referring to professional counseling, and engaging individuals as partners in the management of the condition.
- Participants wanted to engage with their HCPs, but the limited time, combined with HCPs not asking about their concerns or needs, inhibited such conversations. HCPs must assess the situation and guide individuals to express their concerns when they are ready to do so.
- HCPs must refer people diagnosed with type 2 diabetes for DSMES. Electronic referral systems should be used to improve the consistency of referrals and follow-up care.
- The development of materials to cover common education needs of people with a new type 2 diabetes diagnosis would help individuals and HCPs to engage in conversations to address any immediate and pressing concerns.
- Nurses have been instrumental in assisting individuals during health-illness transitions. Therefore, health care systems can leverage nurses to better assist and guide individuals in their transition to living well with diabetes.
- Future studies should determine the feasibility of incorporating services in primary care to better support healthy transitions after a type 2 diabetes diagnosis.

Conclusion

Receiving a diagnosis of diabetes presents several challenges that need to be anticipated and managed properly. Yet, this study identified that individuals' concerns and emotions are not properly addressed at diagnosis. This study demonstrates that individuals want 1) immediate emotional support to address the unexpressed concerns and emotions experienced at

diagnosis, 2) information about available resources to know when and where to seek additional help, and 3) connection with a health care partner after diagnosis who will serve as a guide and assist in the transition. Therefore, health care systems should provide resources for psychological support, designate an HCP as a diabetes coordinator, and provide informational resources to assist individuals who are newly diagnosed with type 2 diabetes. Through such interventions, newly diagnosed individuals can receive the support they need to aid them in their transition and to learn to manage diabetes to ensure improved quality of life and health outcomes.

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DUALITY OF INTEREST

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

AUTHOR CONTRIBUTIONS

M.D.S.B. designed the study and was responsible for data collection and management under the supervision of S.M., D.G., K.V.H., M.B., and J.K. M.D.S.B. wrote the manuscript. S.M., D.G., and J.K. contributed to the analysis and discussion and edited the manuscript. K.V.H. reviewed the manuscript and contributed to discussion. M.B. contributed to analysis and reviewed the manuscript. M.D.S.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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