

Experiences of Diabetes Burnout: A Qualitative Study Among People with Type 1 Diabetes

The evidence affords new insight into this phenomenon.

Diabetes is one of the major health challenges of the 21st century. In the United States, it's estimated that about 12% of the adult population has diabetes,¹ and that percentage is projected to increase to between 25% and 28% by 2050.² The state of Tennessee, where this study was conducted, lies in what has been designated the "diabetes belt,"³ with the sixth highest rate of diabetes (11.4%) in the country.⁴

As used by people with diabetes and health care providers, the term *diabetes burnout* refers to both a psychosocial concept and a condition.⁵ Diabetes burnout can be debilitating and ongoing, often leading to challenges with self-management, suboptimal self-care, a high prevalence of diabetes-associated comorbidities and complications, a decreased quality of life, and increased health care costs.^{5,6} There is evidence suggesting that up to 36% of adults with diabetes identify "feeling burned out" as a primary barrier to treatment adherence.⁷ This finding underscores the importance of identifying at-risk populations early and shortening the duration of burnout in those who experience it. Yet, while the existence of diabetes burnout is widely acknowledged, there is a lack of clarity about its definition, and no measurement tools or interventions exist to address it.

Diabetes burnout has been described as feelings of exhaustion and frustration related to the unre-

lenting daily demands of managing the illness, resulting in inconsistent self-care behaviors.^{8,9} But the literature generally hasn't recognized diabetes burnout as a distinct entity, using the term instead as a synonym for diabetes distress.¹⁰⁻¹² Moreover, the main elements of diabetes burnout—exhaustion, frustration, and inconsistent self-care^{8,9}—are integral parts of the most widely used diabetes distress measures.¹²⁻¹⁵ The failure of measurement tools to differentiate diabetes burnout from diabetes distress magnifies the confusion. When the literature has addressed diabetes burnout, it's looked at how such burnout affects health care providers¹⁶⁻¹⁹ and family caregivers of people with diabetes.²⁰⁻²² It has not addressed diabetes burnout in people with type 1 diabetes. In short, the confounding of diabetes burnout with similar concepts limits our ability to delineate its biological and behavioral mechanisms and identify effective interventions for prevention and management.

In an attempt to clarify the nature of diabetes burnout, we conducted preliminary studies of 35 blog narratives²³ and 32 YouTube videos²⁴ by people with type 1 diabetes. The findings suggested that diabetes burnout involves a combination of emotions and behaviors. Descriptions of burnout included feeling mentally and physically exhausted from dealing with self-care; experiencing detachment from illness

ABSTRACT

Background: People with type 1 diabetes are at increased risk for diabetes burnout, resulting in suboptimal diabetes care and quality of life. While the existence of diabetes burnout is widely acknowledged, there is no evidence-based definition, means of measurement, or interventions to address it.

Objective: This study was aimed at increasing our understanding of the lived experiences of diabetes burnout among adults with type 1 diabetes.

Methods: A qualitative descriptive study was conducted with a sample of 18 adults with type 1 diabetes who reported a current or previous experience of diabetes burnout. Data were collected using in-depth interviews and analyzed using qualitative content analysis.

Results: Four main themes were identified: mental, emotional, and physical exhaustion from having diabetes; detachment from illness identity, diabetes self-care, and support systems; contributing factors to diabetes burnout; and strategies for preventing or overcoming diabetes burnout.

Conclusion: Although exhaustion is an entry point for diabetes burnout, the findings suggest that detachment from illness identity, diabetes self-care, and support systems form a core component. Detachment may explain poor outcomes in individuals experiencing diabetes burnout.

Keywords: diabetes burnout; diabetes distress; self-care; type 1 diabetes

identity (a sense of self as a person with diabetes), diabetes self-care, and support systems; and feeling powerless to reengage in self-care. In these studies, diabetes burnout emerged as a related yet distinct concept from diabetes distress, in which distress is a precursor to burnout. Similarities between diabetes burnout and Maslach's occupational burnout theory—the widely accepted theory that burnout is composed of three components: exhaustion, cynicism, and a sense of inefficacy^{25, 26}—were noted as well.

Although the preliminary studies yielded useful data, the findings were limited in that blog narratives and YouTube videos are self-directed and can be edited. Interviews allow an interviewer to pose questions that might not otherwise be raised and to include prompts that encourage elaboration.

Study purpose. Through in-depth individual interviews in a sample of people with type 1 diabetes, we sought to expand on our previous research and increase our understanding of the lived experiences of diabetes burnout among adults with type 1 diabetes.

METHODS

Design and sampling method. A descriptive qualitative design was used. We employed convenience sampling using a maximum variation technique in order to sample a wide range of respondents. The University of Tennessee, Knoxville's institutional review board approved the study before data collection began.

Participants were recruited at two clinical sites in Appalachian counties in eastern Tennessee. The two sites had different characteristics: one specifically served uninsured adults in a rural area and the other

mainly served insured adults in an urban area. This enhanced the variation of the study population in terms of insurance coverage and residential area.

Flyers describing the study were posted at the target sites. The principal investigator (one of us, SA) and two providers (AV and a nurse) at the target sites also recruited participants through confidential verbal invitations. Another point of attention was the recruiting of “invisible groups.” In our preliminary studies, we realized that people experiencing diabetes burnout can be hard to reach because of their disengagement from self-care behaviors and a tendency to miss medical appointments. To include this specific population, the providers reviewed the electronic health records of people with type 1 diabetes to identify potential participants (those who frequently rescheduled or missed two or more appointments) and contacted them by telephone. Before the study, providers involved in recruitment completed the Collaborative Institutional Training Initiative program in human subject research. They also received an orientation from the principal investigator about the recruitment and screening process. Recruiters followed this process in informing potential participants about the study, confidentiality, and their right to discontinue participation at any time.

Inclusion criteria were having type 1 diabetes; being between the ages of 21 and 65 years; living in the Appalachian counties covered by the study sites; and currently or previously experiencing diabetes burnout, which was screened for by asking two questions: “Has there been a time in the past year in which you felt you were not generally on track with managing your diabetes?” and “Has there been a time in the past year in which you went through

Table 1. Participant Demographics

ID No.	Age	Sex	Race/Ethnicity	Education (highest level attained)	Employment Status	Marriage Status	Health Insurance	Residential Area	Currently Using Insulin Pump	Currently Experiencing Diabetes Burnout
1	37	F	African American	High school	Part time	Married	No	Rural	No	No
2	31	M	African American	College graduate	Part time	Single	No	Rural	Yes	Yes
3	36	F	White	College graduate	Full time	Married	Yes	Rural	Yes	Yes
4	27	F	Hispanic	College graduate	Part time	Single	No	Urban	No	No
5	21	F	White	College graduate	Part time	Single	Yes	Urban	Yes	No
6	41	M	White	College graduate	Full time	Married	Yes	Urban	Yes	Yes
7	42	F	African American	College graduate	Part time	Single	No	Urban	Yes	Yes
8	39	M	White	High school	Full time	Married	Yes	Rural	Yes	No
9	42	M	African American	College graduate	Part time	Married	No	Rural	No	No
10	24	M	White	College graduate	Part time	Single	No	Rural	Yes	No
11	51	F	White	College graduate	Part time	Married	Yes	Rural	Yes	Yes
12	27	M	Hispanic	College graduate	Part time	Single	Yes	Rural	Yes	No
13	47	M	White	College graduate	Full time	Married	Yes	Urban	Yes	No
14	39	F	White	College graduate	Full time	Married	Yes	Rural	Yes	No
15	22	F	African American	College graduate	Part time	Single	No	Urban	Yes	Yes
16	65	F	White	College graduate	Unemployed	Single	No	Rural	No	No
17	64	F	White	College graduate	Part time	Married	Yes	Urban	Yes	No
18	33	F	Hispanic	College graduate	Part time	Married	Yes	Urban	No	Yes

periods of time that you were burned out by your diabetes?” We limited the time frame of past burnout to the past year in order to minimize the impact of recall bias. Recruiting continued until data saturation was reached.

Data collection. When participants who met the inclusion criteria were identified, the principal investigator contacted them by telephone to further explain the study purpose and design, confidentiality, and the right to stop participating; informed consent was then obtained. The principal investigator conducted all interviews.

Data were collected through semistructured individual interviews using an interview guide. Interviews were conducted from July 6 through October 6, 2018, taking place either by telephone (14 participants) or in person (four participants) in an appropriate private location. Interviews started with the question “What stands out in your mind when it comes to diabetes burnout?” and continued with the following three main questions: “How do you behave or feel while experiencing diabetes burnout?,” “What are the driving factors for your diabetes burnout?,” and “How do you prevent or overcome diabetes burnout?” Additional questions asked ad hoc included “Can you provide an example?” and “Can you explain in more detail?” Interviews lasted between 60 and 100 minutes, and participants received a \$20 gift card.

Data analysis. Interviews were audio recorded, transcribed, and coded using NVivo 12 Pro software. Analysis incorporated immersion, reduction, and interpretation phases as described by Sandelowski.²⁷ Two researchers (SA and BS) independently coded all the interviews, and a qualitative research expert (HS) refined the identified categories and themes. The research team shared the interpretations with a group of 10 multidisciplinary qualitative researchers, who critically reviewed the findings. This was done in part to minimize the risk of confirmation bias. The research team then integrated the group’s feedback and reached consensus on the identified themes.

RESULTS

Sample. Twenty-three people met the inclusion criteria and were recruited, but five didn’t follow through with interview participation; no explanation was provided. The final sample consisted of 18 participants with type 1 diabetes between 21 and 65 years of age; the mean age was 38 years. Eleven (61%) were female and seven (39%) were male. Ten (56%) identified as white, five (28%) as African American, and three (17%) as Hispanic. A majority were employed full or part time (94%), were married (56%), were college graduates (89%), and were using an insulin pump (72%). Seven participants (39%) reported currently experiencing diabetes burnout and 11 (61%) had experienced it during the

previous year. (Note that because of rounding, some values may not sum to 100%.) For more demographic details, see Table 1.

Findings. Participants described levels of diabetes burnout that ranged from “feeling burned out” to “being burned out.” They also differentiated diabetes burnout from diabetes distress as “apathy” versus “anxiety.” Four main themes were identified: mental, emotional, and physical exhaustion from having diabetes; detachment from illness identity, diabetes self-care, and support systems; contributing factors to diabetes burnout; and strategies for preventing or overcoming diabetes burnout. Table 2 offers an overview of the study themes, categories, and supporting data.

Theme 1: Mental, emotional, and physical exhaustion from having diabetes. Participants reported that the experience of diabetes burnout began with strong feelings of mental, emotional, and physical exhaustion. They acknowledged that it was easy to get tired of dealing with their illness and difficult to recoup; as one participant said, diabetes is something that “never goes away.” Several participants described struggling to undertake self-care behaviors while feeling burned out.

I try to take it in stride as best I can . . . even if I felt burned out, I’ve still got to check my blood sugar. I still got to give [my body] a shot. I still got to keep track of all of it. It doesn’t matter if I felt burned out about it. I still got to do it. I don’t want to have more complications.—Participant No. 9, a 42-year-old man

Eleven participants spoke of the mental and emotional exhaustion that results from the constant demands of diabetes care. A comment by participant No. 12, a 27-year-old man, was representative: “I am just tired of the constant attention to details day after day, after day, after day.” Similarly, participant No. 14, a 39-year-old woman, spoke of “the pressure of struggling with a lot of thinking and calculating.” Another participant said,

It’s exhausting, it is exhausting. It really is, to constantly take care of yourself and have to worry about everything you eat, everything you do, every move you make.—Participant No. 3, a 36-year-old woman

Several participants pointed to being physically tired from dealing with daily self-care and having a body that is, as one put it, “totally out of whack.” A comment by participant No. 15, a 22-year-old woman, was typical: “You’re tired all the time, I mean physically, you’re just feeling old, feeling worn out.” Participant No. 12, a 27-year-old man, spoke of how the lack of physical energy

affected his self-care behaviors: “When you go home, you just want to eat whatever’s available and go to bed.”

Theme 2: Detachment from illness identity, diabetes self-care, and support systems. All but one of the participants described mentally and emotionally detaching from their illness identity as a way to seek normalcy after living with diabetes for several years. Participant No. 17, a 64-year-old woman, described being burned out as “apathy,” a feeling that overcame her “entire being” and kept her from “moving forward.” The following comments were typical:

I didn’t want to think about diabetes and I didn’t want to be a diabetic anymore.—Participant No. 9, a 42-year-old man

I don’t want anything to make me think about being a diabetic. It’s a beautiful illusion to have, where most of the time you exist as a healthy person.—Participant No. 13, a 47-year-old man

Several participants indicated reaching a point of apathy. Participant No. 11, a 51-year-old woman, said, “I’ve had enough, I would rather deal with the

result of the disease.” Some consciously decided to “put diabetes self-care on hold for a little while,” as participant No. 10, a 24-year-old man, stated. Another said,

Burnout is apathy. Just not caring. When you have given up fighting against the struggles that you have had, the distress, the fault of the things—that leads to the burnout.—Participant No. 8, a 39-year-old man

All the participants reported physical detachment and disengagement from diabetes self-care behavior. Some were able to return to their self-care regimen within a short time, which varied from hours to days. But for most participants, such disengagement lasted from weeks to months and sometimes years.

I didn’t check my blood sugars . . . I wouldn’t adjust my pump, I didn’t really count my carbs . . . I forgot to give my insulin . . . I just kept enough insulin in me to not put me in the hospital or to not go [into diabetic ketoacidosis]. I gained 10 pounds. Just no exercise, eating terrible.—Participant No. 15, a 22-year-old woman

Table 2. Overview of Study Findings

Theme	Category	No. of Participants Whose Comments Support the Theme	No. of Supporting References in the Transcripts
Mental, emotional, and physical exhaustion from having diabetes	• Mental and emotional exhaustion	11	23
	• Physical exhaustion	7	12
Detachment from illness identity, diabetes self-care, and support systems	• Mental detachment from illness identity	17	56
	• Physical detachment from diabetes self-care	18	116
	• Mental and physical detachment from other people	9	17
Contributing factors to diabetes burnout	• The burden of diabetes self-care	15	82
	• Lack of accomplishment in achieving diabetes goals	14	50
	• Lack of psychosocial support	12	46
	• Culture of perfectionism in diabetes care	16	78
	• The occurrence of significant or destabilizing life events	11	31
Strategies for preventing or overcoming diabetes burnout	• Acknowledge burnout and retake ownership of diabetes	16	51
	• Connect with support systems	14	66
	• Have a positive mindset	11	21

Elevated glycated hemoglobin levels and experiencing diabetic ketoacidosis or requiring emergency hospitalization were common consequences if disengagement was of extended duration.

Many participants reported feeling “down” and becoming withdrawn, disconnecting from their support systems to protect themselves from the judgments of others they felt didn’t “truly understand and care” about what they were going through. Some participants described detaching from their providers by taking an apathetic approach during office visits—they stopped asking questions and showed a lack of interest in their treatment; some simply cancelled appointments. Detachment was also used as a protective strategy by some participants who didn’t want to “burden and hurt” family members and friends. But such avoidance eventually caused further detachment.

It’s feeling like you’re burdening somebody . . . I don’t like to put that on anybody else, I don’t want to make them hurt because [I’m] hurting. . . . So just trying to pretend like, I might have the stomach flu or something like that, when friends and family are like, “Why do you feel so sick?” And so just trying to cover up, like, I’m just really not taking my insulin or I’m not testing my blood sugars.—Participant No. 13, a 47-year-old man

After a period of being detached from self-care, many participants reported feeling powerless, often combined with feelings of guilt, fear, and self-blame. One participant described how she felt when she was “out of whack”:

I felt awful, but at the same time, I just wanted to stay stuck where I was. I didn’t have the power to take action.—Participant No. 1, a 37-year-old woman

Theme 3: Contributing factors to diabetes burnout. Participants described the “snowball effect” of the many factors that trigger diabetes burnout. They identified the constant burden of diabetes self-care (15 participants) and failure to achieve diabetes goals such as blood glucose control (14 participants) as the main contributors to burnout. They also indicated that these factors could be magnified by a culture of perfectionism in diabetes care, a lack of psychosocial support, and the occurrence of significant life events.

Diabetes was perceived as an unpredictable inconvenience that mandates complex and demanding self-care behaviors. The frequent interruptions necessary for self-care in the middle of daily life left many participants feeling “ripped from the moment,” and contributed to their burnout.

Having to test your blood sugar all day when you have other things going on? Not what you want to be worrying about. Waking up in the middle of the night? Low blood sugars at times that are inconvenient? Just that happening over and over again. I think you experience burnout.—Participant No. 2, a 31-year-old man

Participant No. 5, a 21-year-old woman, spoke of being “fed up with trying and seeing yoyo patterns” in her blood glucose levels, adding “no matter how hard I try on it, I can’t get the perfect result.” Comments by other participants indicated that feeling a lack of accomplishment, as reflected by an inability to achieve blood glucose control or by the development of new diabetes-related complications, triggered physical detachment.

Participants spoke of the significance of social, cultural, and contextual factors that affected their burnout experience. Almost all had experienced a lack of support at some point, and for some this seemed to lead to a detachment phase. As one participant explained,

I just didn’t have a support system or anyone to confide in, to talk to. When I try to handle things on my own, that’s when things get just out of control.—Participant No. 4, a 27-year-old woman

While valuing informal support from family and friends, participants expressed a desire for a specialized, holistic care approach from their providers. A paternalistic attitude from providers contributed to diabetes burnout:

I’ve had doctors in the past standing over [me] going, “You have to do this, you have to do that.” . . . You just get angry, you feel like a kid, you want to rebel.—Participant No. 7, a 42-year-old woman

Both a lack of psychosocial support from providers and the unsupportive atmosphere of diabetes clinics were discussed as contextual factors contributing to burnout.

There’s plenty of brochures that warn you about your feet, what to eat. But where’s all the stuff about all the emotional state[s] you’re gonna feel? You’re pretty much left on your own to deal with burnout; even going to your doctor, he’s only treating your disease. When you’re in those waiting rooms, you’re immersed in sickness.—Participant No. 6, a 41-year-old man

Participants criticized the existing culture of perfectionism in diabetes care. As participant No. 1, a 37-year-old woman, noted, “Everything is just constantly based on having the perfect numbers.” Several others mentioned their difficulty with the unrelenting nature of perfectionism. Participant No. 7, a 42-year-old woman, said, “Everything is supposed to be perfect, but it is not. It’s like constant struggle.” Having blood glucose levels out of the desired range was perceived as failure. Participant No. 14, a 39-year-old woman, said, “It’s hard to keep it perfect in that range. You can’t get it perfect, and it makes me feel like crap.” A few participants cited periods of obsessive or overly engaged self-care that preceded detachment.

I feel like I’m not doing good enough or as good as I could be. I just feel like it could be better than a 6.5. The reason it’s a 6.5 is because I check my blood sugar 12 times a day, I’m constantly checking my blood sugar to not go out of range. . . . I just try to stay on top of my blood sugar and it gets pretty exhausting.—Participant No. 2, a 31-year-old man

Participants also discussed destabilizing life events that had increased the burden of self-care or adversely affected their ability to achieve target blood glucose levels (or both). Some described detaching from self-care during the transition from the strictures of childhood routines to the freedom of adulthood. They described how the increasing responsibilities that accompanied starting college, a new job, or a marriage led to diabetes burnout. Yet such burnout was not limited to younger adults. Several older participants named difficulties in balancing diabetes management with the demands of holding full-time jobs, raising kids, taking vacations, and experiencing other health problems or changes to treatment plans as antecedents to burnout.

Theme 4: Strategies for preventing or overcoming diabetes burnout. Participants discussed the following strategies: acknowledging burnout and retaking ownership of diabetes (16 participants), connecting with support systems (14 participants), and having a positive mindset (11 participants) that focuses on the benefits of diabetes management.

Acknowledging burnout and retaking ownership of diabetes. When burnout occurred, a common first response was to want to “ignore it.” But many participants reported that, after spending some time in such avoidance, they had revelations about their health that served to help them retake ownership. This was the main strategy used for overcoming burnout. Participants reflected on the risk of complications, reclaimed their identity as a person with type 1 diabetes, and acknowledged the importance of treatment.

It was to a point in my life where I was like . . . I’m not gonna be able to survive long doing what I’m doing. I think after a while I realize[d] it doesn’t help for me to sit in self-pity. I have to be active about this . . . burnout is not gonna help anything.—Participant No. 13, a 47-year-old man

Connecting with support systems. Acknowledging their burnout and retaking ownership of their health helped participants to reconnect with available support systems and pursue efforts to start self-care from scratch. Several participants noted that providers who engaged them in a judgment-free conversation about self-care made a significant difference.

Finally, I met a new endocrinologist. He was just so kind and genuine to me. . . . He was very encouraging to me, he made me want to take care of myself. He wasn’t yelling at me or anything like I had with the previous doctor. I want my doctor to look at me and say, “Wow, you know, let’s figure out why you’re doing this . . . then we can solve the problem.”—Participant No. 15, a 22-year-old woman

Several participants spoke of reconnecting with family and friends who provided them with the motivation they needed to resume self-care.

My friends, my family are very supportive and so when they know that I’m burned out, then they’re pretty quick to step in and help me out and try to cheer me up. . . . It also helps to know that I have people in my corner [who] are going to walk through this with me, that I’m not alone in any of this.—Participant No. 4, a 27-year-old woman

Having a positive mindset. Participants highlighted the significance of positive mindsets to overcome their diabetes struggles and prevent burnout. Participant No. 11, a 51-year-old woman, said, “I really try to focus on the positive things . . . here’s the progress I’ve made.” Many participants motivated themselves by focusing on what they felt mattered more than diabetes, such as their jobs, personal desires, and families and loved ones.

I combat my burnout by reminding myself of what’s more important. I’m getting to see my daughter grow up, I get to still work and do the practice that I love, I get to see new things and do things, and I have to remind myself of that, and that’s how I combat it. . . . Be thankful for what you got.—Participant No. 7, a 42-year-old woman

Several participants pointed to stress reduction techniques to help them maintain a positive mindset. As participant No. 8, a 39-year-old man, said, “I started going to the gym every other day . . . I’m running two miles pretty quickly, so I’ve made a lot of progress to stay on track.”

DISCUSSION

From participants’ accounts, we posited the following definition of diabetes burnout: a state of mental, emotional, and physical exhaustion following an apathetic detachment from one’s illness identity, diabetes self-care behaviors, and support systems, which is commonly accompanied by a feeling of powerlessness. This description of diabetes burnout aligns with our preliminary findings.^{23,24} Moreover, the findings indicate that while diabetes distress and early-stage diabetes burnout (characterized by exhaustion) may overlap conceptually and appear similar, later-stage diabetes burnout (characterized by detachment) is actually distinct from diabetes distress.

depersonalization, or actively ignoring the qualities that make others unique and engaging—is a second key component of burnout.^{25,26} Our findings support this too; we found that diabetes burnout might center on detachment from oneself as a person with diabetes, diabetes self-care, and support systems. As for the third key component in Maslach’s burnout theory, inefficiency, we believe this correlates with our finding that a lack of accomplishment in achieving diabetes goals was a driving factor for burnout.

Going beyond Maslach, our findings suggest that a feeling of powerlessness—manifested as an inability to retake ownership of and engagement with diabetes care—accompanies diabetes burnout. Regarding occupational burnout, Maslach and Leiter have stated that “exhaustion alone is not a proxy for burnout” and that cynicism (detachment and depersonalization) is the dominant profile of burnout.²⁶ Powerlessness isn’t mentioned. The literature on coping is relevant here. Folkman and

Participants described levels of diabetes burnout that ranged from ‘feeling burned out’ to ‘being burned out.’

As noted earlier, Maslach’s occupational burnout theory posited that exhaustion is a key component of burnout,^{25,26} and this study’s findings offer support in the context of living with type 1 diabetes. Indeed, among our participants, exhaustion was identified as the primary entry point for diabetes burnout. Exhaustion covers the lack of mental, emotional, and physical energy necessary for an enduring engagement with diabetes-related self-care. Our findings suggest that there might be a certain level of exhaustion that becomes the tipping point at which a person moves from distress into burnout, and which might subsequently prompt detachment from illness identity, diabetes self-care, and support systems.

During detachment, participants reported consciously ignoring almost all aspects or the most challenging aspects of diabetes self-care for some period of time. These included insulin injections, insulin dose adjustments, pump exchange, diet (including carbohydrate counting), exercise, blood glucose monitoring, and follow-up appointments. Such detachment appears to be conceptually distinct from distress.

Maslach also posited that cynicism—an attempt to distance oneself from other people through

Moskowitz have described detachment as a disengagement strategy (characterized by avoidance, denial, wishful thinking, and even substance abuse) that people used to escape stressors and prevent further exhaustion.²⁸ But detachment from diabetes care is a poor coping strategy, given the permanent and complex nature of the disease. And because detachment can offer short-term relief, it’s possible that over time it could weaken a person’s motivation to reengage in self-care.

Further studies are needed to elucidate the relationship between diabetes distress and diabetes burnout. For example, to create effective interventions, it’s essential that we learn whether there are additional entry points to burnout besides exhaustion and explore the mechanisms underlying detachment. We also need to understand what keeps some people in detachment for long periods.

The study findings suggest that, among people living with type 1 diabetes, there may be a spectrum from a milder “feeling burned out” to a more severe “being burned out” that captures how they relate to self-care in both feelings and actions. Conceptually, such a spectrum could allow for the existence of different diabetes burnout profiles, similar to those

discussed in occupational burnout literature.²⁹⁻³¹

Based on the data from this study and our earlier research, we hypothesize that there are at least four distinct profiles in relation to diabetes burnout, as follows:

- *Engaged profile*: the person is dedicated to diabetes self-care and doesn't exhibit exhaustion, detachment, or powerlessness.
- *Exhausted profile*: the person remains physically engaged in diabetes self-care and with support systems but describes "feeling" burned out and exhausted.
- *Disengaged profile*: the person is disengaged from one or more of these aspects—diabetes self-care, illness identity, support systems—but does not exhibit exhaustion or powerlessness.
- *Burned-out profile*: the person exhibits mental, emotional, and physical detachment from illness identity, diabetes self-care, and support systems. This is generally accompanied by exhaustion or powerlessness (or both).

It's important that providers acknowledge the challenges of living with diabetes and don't convey expectations of perfectionism.

In keeping with early descriptions of diabetes burnout,^{8,9} this study identified two main contributing factors to such burnout: the burden of diabetes self-care and a lack of accomplishment in achieving diabetes goals. The study also revealed contextual and cultural contributing factors, including a culture of perfectionism in diabetes care, a lack of psychosocial support, and the occurrence of significant or destabilizing life events. Most of these findings are in keeping with findings from other studies in people with diabetes.^{10, 12}

Participants in our study acknowledged the importance of accepting the possibility of diabetes burnout, connecting to support systems, developing a positive mindset, and reducing stress in order to prevent or overcome burnout. This is consistent with findings from studies on diabetes distress^{10, 12} and occupational burnout.^{26, 29, 31}

Lastly, the results from both this study and our preliminary studies indicate that there are three core components of diabetes burnout: exhaustion, detachment, and powerlessness. More research to

confirm this, and to examine relationship patterns among these components, is vital to confirm whether our hypothetical profiles reflect reality.

Limitations. This study was conducted with a small sample of people with type 1 diabetes in Tennessee, and the findings can't be generalized to the total population of people with diabetes. Participants were recruited through convenience sampling; as a result, some perspectives may be over- or under-represented in this study. The study relied on participants' memories about their current or past burnout experiences, which may be subject to some degree of recall and self-report biases. Most interviews were conducted by telephone, and this might result in a different quality of data than that gathered in face-to-face interviews. The interviewer, who was not from Appalachia, would generally be considered an "outsider"; this cultural difference may have influenced participants' responses to questions.

Implications for practice. Hearing participants' voices on the page and seeing how they describe their diabetes burnout experiences can help nurses and other providers to better understand the underlying factors and challenges. It's vital that providers ask people with type 1 diabetes about diabetes burnout during regular follow-up visits, especially when there are indications that they're struggling to manage their blood glucose or are facing major life events. Providers should encourage people with type 1 diabetes, particularly those who may be burned out, to participate in open and nonjudgmental discussions about their level of exhaustion, the degree to which they're engaged or lacking in self-care, and their options for support. During such conversations, it's important that providers acknowledge the challenges of living with diabetes and don't convey expectations of perfectionism about diabetes self-care.

CONCLUSION

The findings of this study contribute to a formative understanding of diabetes burnout as distinct from diabetes distress, and offer a basis from which researchers can continue exploring. Further research will help to deepen our understanding of such burnout, develop the necessary clinical tools for its detection and measurement, and create effective evidence-based interventions. ▼

For more than 50 additional continuing education activities on the topic of diabetes, go to www.nursingcenter.com/ce.

Samereh Abdoli is an assistant professor in the College of Nursing, University of Tennessee, Knoxville, where Amit Vora is a clinical assistant professor in the Graduate School of Medicine. Danielle Hessler is an associate professor in the Department of Family and

Community Medicine, University of California, San Francisco. Betsy Smither is a project manager at Oak Ridge Associated Universities, Oak Ridge, TN. Heather Stuckey is an associate professor in the Departments of Medicine, Public Health Science, and Humanities at Pennsylvania State University, Harrisburg. This study was supported in part by an unrestricted grant from the Beryl Institute. Contact author: Samereh Abdoli, sabdoli@utk.edu. The authors and planners have disclosed no potential conflicts of interest, financial or otherwise.

REFERENCES

- Centers for Disease Control and Prevention. *National diabetes statistics report, 2017. Estimates of diabetes and its burden in the United States*. Atlanta; 2017. <https://www.cdc.gov/diabetes/pdfs/data/statistics/national-diabetes-statistics-report.pdf>.
- Boyle JP, et al. Projection of the year 2050 burden of diabetes in the US adult population: dynamic modeling of incidence, mortality, and prediabetes prevalence. *Popul Health Metr* 2010;8:29.
- Barker LE, et al. Geographic distribution of diagnosed diabetes in the U.S.: a diabetes belt. *Am J Prev Med* 2011;40(4):434-9.
- Centers for Disease Control and Prevention. *Diabetes report card 2017*. Atlanta; 2018. <https://www.cdc.gov/diabetes/pdfs/library/diabetesreportcard2017-508.pdf>.
- Culman M, et al. Diabetes burnout—review. *Proceedings of the Romanian Academy. Series B, Chemistry, life sciences, and geosciences*. 2018;18(1):25-30.
- Polonsky WH. *Diabetes burnout: what to do when you can't take it anymore*. Alexandria, VA: American Diabetes Association; 1999.
- Nelson LA, et al. Assessing barriers to diabetes medication adherence using the Information-Motivation-Behavioral skills model. *Diabetes Res Clin Pract* 2018;142:374-84.
- Hoover JW. Patient burnout, and other reasons for non-compliance. *Diabetes Educ* 1983;9(3):41-3.
- Polonsky WH. Understanding and treating patients with diabetes burnout. In: Anderson BJ, Rubin RR, editors. *Practical psychology for diabetes clinicians*. New York, NY: McGraw-Hill Companies, Inc.; 1996. p. 193-2.
- Beverly EA, et al. Is diabetes distress on your radar screen? *J Fam Pract* 2017;66(1):9-14.
- Dennick K, et al. What is diabetes distress and how can we measure it? A narrative review and conceptual model. *J Diabetes Complications* 2017;31(5):898-911.
- Fisher L, et al. Understanding the sources of diabetes distress in adults with type 1 diabetes. *J Diabetes Complications* 2015;29(4):572-7.
- Fisher L, et al. Development of a brief diabetes distress screening instrument. *Ann Fam Med* 2008;6(3):246-52.
- Polonsky WH, et al. Assessing psychosocial distress in diabetes: development of the Diabetes Distress Scale. *Diabetes Care* 2005;28(3):626-31.
- Welch GW, et al. The problem areas in diabetes scale: an evaluation of its clinical utility. *Diabetes Care* 1997;20(5):760-6.
- Beverly EA, et al. Understanding physicians' challenges when treating type 2 diabetic patients' social and emotional difficulties: a qualitative study. *Diabetes Care* 2011;34(5):1086-8.
- Charman D. Burnout and diabetes: reflections from working with educators and patients. *J Clin Psychol* 2000;56(5):607-17.
- Childs BP. The complexity of diabetes care. *Diabetes Spectr* 2005;18(3):130-1.
- Hanson CL. Understanding and treating provider burnout. In: Anderson BJ, Rubin RR, editors. *Practical psychology for diabetes clinicians*. 2nd ed. New York, NY: McGraw-Hill Companies, Inc.; 2002. p. 173-81.
- Grover S, et al. Coping and caregiving experience of parents of children and adolescents with type-1 diabetes: an exploratory study. *Perspect Clin Res* 2016;7(1):32-9.
- Lindstrom C, et al. Group intervention for burnout in parents of chronically ill children—a small-scale study. *Scand J Caring Sci* 2016;30(4):678-86.
- Lindstrom C, et al. Parental burnout in relation to sociodemographic, psychosocial and personality factors as well as disease duration and glycaemic control in children with type 1 diabetes mellitus. *Acta Paediatr* 2011;100(7):1011-7.
- Abdoli S, et al. Improving diabetes care: should we reconceptualize diabetes burnout? *Diabetes Educ* 2019;45(2):214-24.
- Abdoli S, et al. Descriptions of diabetes burnout from individuals with type 1 diabetes: an analysis of YouTube videos. *Diabet Med* 2019 Jun 5 [Epub ahead of print].
- Maslach C. Burnout: a multidimensional perspective. In: Schaufeli WB, et al., editors. *Professional burnout: recent developments in theory and research*. Philadelphia: Taylor and Francis; 1993. p. 19-32.
- Maslach C, Leiter MP. Understanding the burnout experience: recent research and its implications for psychiatry. *World Psychiatry* 2016;15(2):103-11.
- Sandelowski M. Qualitative analysis: what it is and how to begin. *Res Nurs Health* 1995;18(4):371-5.
- Folkman S, Moskowitz JT. Coping: pitfalls and promise. *Annu Rev Psychol* 2004;55:745-74.
- Farber BA. Introduction: Understanding and treating burnout in a changing culture. *J Clin Psychol* 2000;56(5):589-94.
- Montero-Marín J, García-Campayo J. A newer and broader definition of burnout: validation of the "Burnout Clinical Subtype Questionnaire (BCSQ-36)." *BMC Public Health* 2010;10:302.
- Montero-Marín J, et al. A new definition of burnout syndrome based on Farber's proposal. *J Occup Med Toxicol* 2009;4:31.

CE CONNECTION

Earn CE Credit online:
Go to www.nursingcenter.com/ce/ajn and receive a certificate within minutes.

TEST INSTRUCTIONS

- Read the article. Take the test for this CE activity online at www.nursingcenter.com/ce/ajn.
- You'll need to create and log in to your personal CE Planner account before taking online tests. Your planner will keep track of all your Lippincott Professional Development (LPD) online CE activities for you.
- There is only one correct answer for each question. The passing score for this test is 13 correct answers. If you pass, you can print your certificate of earned contact hours and the answer key. If you fail, you have the option of taking the test again at no additional cost.
- For questions, contact LPD: 1-800-787-8985.
- Registration deadline is December 3, 2021.

PROVIDER ACCREDITATION

LPD will award 1.5 contact hours for this continuing nursing education (CNE) activity. LPD is accredited as a provider of CNE by the American Nurses Credentialing Center's Commission on Accreditation.

This activity is also provider approved by the California Board of Registered Nursing, Provider Number CEP 11749 for 1.5 contact hours. LPD is also an approved provider of CNE by the District of Columbia, Georgia, and Florida #50-1223. Your certificate is valid in all states.

PAYMENT

The registration fee for this test is \$17.95.