

# Diabetes distress in Veterans with type 2 diabetes mellitus: Qualitative descriptive study

Journal of Health Psychology  
1–15

© The Author(s) 2024

Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/13591053241233387

journals.sagepub.com/home/hpq



Allison A Lewinski<sup>1,2</sup> , Abigail Shapiro<sup>1</sup> ,  
Matthew J Crowley<sup>1,3</sup>, Chelsea Whitfield<sup>1</sup>,  
Joanne Roman Jones<sup>1,4</sup>, Amy S Jeffreys<sup>1</sup>,  
Cynthia J Coffman<sup>1,5</sup>, Teresa Howard<sup>1</sup>,  
Eleanor McConnell<sup>1,6</sup>, Paula Tanabe<sup>2,7</sup>,  
Susan Barcinas<sup>8</sup> and Hayden B Bosworth<sup>1,2,9,10,11</sup>

## Abstract

Diabetes distress (DD) is a negative psychosocial response to living with type 2 diabetes mellitus (T2DM). We sought insight into Veterans' experiences with DD in the context of T2DM self-management. The four domains in the Diabetes Distress Scale (i.e. regimen, emotional, interpersonal, healthcare provider) informed the interview guide and analysis (structural coding using thematic analysis). The mean age of the cohort ( $n=36$ ) was 59.1 years (SD 10.4); 8.3% of patients were female and 63.9% were Black or Mixed Race; mean A1C was 8.8% (SD 2.0); and mean DDS score was 2.4 (SD 1.1), indicating moderate distress. Veterans described DD and challenges to T2DM self-management across the four domains in the Diabetes Distress Scale. We found that (1) Veterans' challenges with their T2DM self-management routines influenced DD and (2) Veterans experienced DD across a wide range of domains, indicating that clinical interventions should take a "whole-person" approach.

<sup>1</sup>Durham Center of Innovation to Accelerate Discovery and Practice Transformation Durham Veterans Health Care System, Durham, NC, USA

<sup>2</sup>Duke University School of Nursing, Durham, NC, USA

<sup>3</sup>Division of Endocrinology, Diabetes and Metabolism, Department of Medicine, Duke University School of Medicine, Durham, NC, USA

<sup>4</sup>Department of Nursing, Manning College of Nursing and Health Sciences, University of Massachusetts Boston, Boston, MA, USA

<sup>5</sup>Department of Biostatistics and Bioinformatics, Duke University School of Medicine, Durham, NC, USA

<sup>6</sup>Geriatric Research, Education and Clinical Center (GRECC), Durham Veterans Affairs Health Care System, Durham, NC, USA

<sup>7</sup>Division of Hematology, Department of Medicine, Duke University School of Medicine, Durham, NC, USA

<sup>8</sup>College of Education, North Carolina State University, Raleigh, NC, USA

<sup>9</sup>Department of Population Health Sciences, Duke University School of Medicine, Durham, NC, USA

<sup>10</sup>Division of General Internal Medicine, Department of Medicine, Duke University School of Medicine, Durham, NC, USA

<sup>11</sup>Department of Psychiatry and Behavioral Sciences, Duke University School of Medicine, Durham, NC, USA

## Corresponding author:

Allison A Lewinski, Durham Center of Innovation to Accelerate Discovery and Practice Transformation, Durham Veterans Affairs Medical Center, HSR&D COIN (558/152), 508 Fulton Street, Durham, NC 27705, USA.

Email: Allison.lewinski@duke.edu

**Trial Registration:** NCT04587336

## Keywords

Diabetes mellitus, qualitative research, self-management, type 2, Veterans

## Background

Diabetes presents a significant public health challenge in the United States: an estimated 11.3% of the population has diabetes, with 38% of adults having pre-diabetes (Centers for Disease Control and Prevention, 2023). Diabetes distress (DD) occurs when an individual is overwhelmed with type 2 diabetes mellitus (T2DM), the amount and frequency of related self-management behaviors, and the knowledge that T2DM is progressive and incurable (Fisher et al., 2013). Negative feelings about T2DM self-management may impede attention to critical self-management behaviors such as healthful eating or checking blood glucose (Ahola and Groop, 2013; Laranjo et al., 2015).

Diabetes distress is subjective and person-specific; it may fluctuate over time or be continually present (Adriaanse et al., 2008; Aikens et al., 2014; Fisher et al., 2013). DD levels negatively correlate with self-management behaviors such as monitoring diet and blood glucose or engaging with providers (Dennick et al., 2017; Perrin et al., 2017; Sturt et al., 2015; Tanenbaum et al., 2013, 2016). High to moderate levels of DD are related to poorer glucose regulation (Adriaanse et al., 2008), higher A1C (Berry et al., 2015), lower medication use (Chew et al., 2018), and poorer quality of life (Carper et al., 2014). DD may be experienced differently among populations facing disproportionate challenges to engagement in T2DM self-management.

Veterans comprise 7% of the adult population in the United States (Vespa, 2020). The Veterans Health Administration (VHA), the largest integrated health care system in the US, serves approximately 9 million enrolled Veterans yearly (Bokhour et al., 2022; Veterans Health Administration, 2023). An estimated 20%–25% of Veterans are diagnosed with diabetes (Veterans Health Administration, 2016),

an incidence two times higher than estimated rates within the national population. Veterans with T2DM may experience DD differently than non-Veterans due to military experience and the cumulative nature of military service. Consideration of Veterans' experiences of DD is critical to developing effective patient-centered interventions to improve self-management and health outcomes; therefore, the primary purpose of this study sought to obtain insight into Veterans' experiences of DD in the context of T2DM self-management.

## Methods

We selected a qualitative descriptive study approach (Sandelowski, 2000, 2010) to further examine DD domains described by the *Diabetes Distress Scale* (Fisher et al., 2012) as well as those identified in our prior work (Lewinski et al., 2021). We conducted interviews during December 2020 through April 2021. The local VHA Institutional Review Board approved all study activities (Protocol #02284).

### *Diabetes distress*

We operationalized DD using the 17-item *Diabetes Distress Scale*, which measures four domains (Fisher et al., 2012): *regimen* (distress specific to engaging in T2DM self-management); *emotional* (feelings of guilt, shame, and worry about living with T2DM); *interpersonal* (distress in interpersonal relationships); and *provider* (interactions with one's healthcare provider in the context of T2DM management).

### *Setting, sample, and recruitment*

Our team conducted qualitative interviews as part of an explanatory sequential mixed methods study (Creswell, 2014) to examine DD in

**Table 1.** Example interview questions.

- 
1. Overall, how do you feel about your diabetes diagnosis?
  2. What do you feel you do well in regards to your diabetes?
  3. Is there anything about being a Veteran that influences how you take care of your diabetes?
  4. Some people experience *diabetes distress*, a term which describes distress and negative emotions related to living with diabetes and having to self-manage every day. How does this term describe your experience taking care of your diabetes?
  5. Some people experience *diabetes stigma*, which describes shame, blame, or feeling different because of their diabetes diagnosis. How does this term describe your experience having diabetes?
- 

Veterans with T2DM. All work was completed at a VHA-affiliated hospital system in the Southeastern United States. Study eligibility included (a) diagnosis of T2DM, (b) documentation of A1C within the past 180 days, (c) ability to speak English, and (d) ability to provide informed consent. A research assistant validated the Veteran's T2DM diagnosis and A1C level using the electronic health record. To obtain diverse responses about DD and T2DM self-management, we balanced the sample of qualitative interviews upon A1C (<9%, ≥9%), medication (insulin, no insulin), and *Diabetes Distress Scale* score (low, moderate, high). We aimed to recruit 36 Veterans to ensure diverse viewpoints on diabetes distress and reach information power (Malterud et al., 2016) on how DD differed by A1C, medication, and Diabetes Distress Scale score. A study research assistant invited Veterans to complete semi-structured interviews following the completion of a survey.

### Data collection and measures

**Demographic data and interview conduct.** A research assistant obtained participant consent and collected self-reported demographic data (e.g. age, gender, race) via telephone. All interviews were conducted via telephone by an experienced qualitative analyst with training in trauma-informed care, recorded, and ranged from 25 to 65 minutes. Interview recordings were de-identified and transcribed by a professional transcription service. Veterans received \$30 for completing an interview.

**Interview questions and probes.** The interview guide (Table 1) addressed the four domains in

the *Diabetes Distress Scale* to elicit Veterans' descriptions of DD in the context of T2DM self-management. Interview questions asked about additional facets of DD, including access to care, having other illnesses in addition to T2DM, changes in emotions and behaviors, living long-term with diabetes, military experience, physical limitations and pain, and stigma (Lewinski et al., 2021). To obtain rich data, we used probes and follow-up questions to elicit participants' experiences of, and strategies for, self-managing T2DM (Drabble et al., 2016).

**Analytic strategy.** We conducted thematic data analysis (Guest et al., 2012) using NVivo (QSR International Pty Ltd) software. Coding and analysis of data was led by a coding team comprised of the qualitative analyst and primary investigator, both of whom are non-Veterans, have advanced research training, and identify as cis-gendered White women. The coding team met weekly during data collection and analysis to identify emerging areas, refine the interview guide, and address emergent questions (Sandelowski, 1995). The team first coded transcripts using a priori structural codes informed by the domains in the *Diabetes Distress Scale* (Fisher et al., 2012) and findings from our prior work (Lewinski et al., 2021), after which they independently read all transcripts and identified appropriate coding units for each a priori structural code prior to beginning coding. Findings were discussed until agreement was reached on coding definitions and their application to these data. The coding team next reviewed code reports for each a priori structural code and used thematic analysis to identify similarities and differences pertaining to specific DD domains within codes.

**Table 2.** Demographic data on Veteran respondents.

	Total (n = 36)
	n (%)
Age – mean (SD)	59.1 (10.4)
Hemoglobin A1c	
<9%	19 (52.8)
≥9%	17 (47.2)
Sex	
Male	33 (91.7)
Female	3 (8.3)
Ethnicity	
Hispanic	2 (5.6)
Non-Hispanic	34 (94.4)
Race	
Black	22 (61.1)
White	11 (30.6)
Mixed race	1 (2.8)
Other race	3 (8.3)
Marital status	
Married	19 (52.8)
Not married	17 (47.2)
Education	
Less than high school	0 (0)
High school graduate/GED	12 (33.3)
Some college	16 (44.4)
College grade or higher	8 (22.2)
Employment	
Employed	13 (36.1)
Not employed	23 (63.9)
Medications	
Insulin	18 (50.0)
No insulin	18 (50.0)
Income <sup>a</sup>	
Less than \$30,000	9 (25.7)
\$30,000–\$59,999	16 (45.7)
More than \$60,000	10 (28.6)
Impact of coronavirus on answers	
Moderate or greater extent	20 (55.6)
None to small extent	16 (44.4)
<i>Diabetes Distress Scale</i> total score – mean (SD)	2.4 (1.1)
Diagnosis of additional comorbidities	
Hypertension	33 (91.7)
Hyperlipidemia	32 (88.9)
Chronic kidney disease	4 (11.1)
Post-traumatic stress disorder	12 (33.3)
Depression	16 (44.4)
Anxiety	6 (16.7)

<sup>a</sup>One patient did not answer the income question.

**Validity and reliability.** Validity and reliability of findings and the iterative generation of codes was ensured by working closely as a coding team (Creswell and Plano Clark, 2011). The coding team provided rich descriptions of all codes and themes, discussed coding until consensus was reached for each code and theme, triangulated data from quantitative and qualitative sources, and presented any discrepant information (Creswell and Plano Clark, 2011). The codebook described the codes and emerging themes and served as an audit trail. Regular study team meetings ensured validity and reliability, higher level code development, and discussion of emerging findings.

## Results

We present the findings in two sections. First, we describe the four themes that relate to the domains of the *Diabetes Distress Scale*. Second, we present themes for three additional facets of DD identified in our prior work.

## Sample

The sample ( $n=36$ ) is fully described in Table 2. Of the respondents, 8.3% were female, 61.1% Black, 30.6% White, 2.8% Mixed Race, and 50% on insulin. The mean age of the cohort was 59.1 years (SD 10.4), mean A1c was 8.8% (SD 2.0), and mean *Diabetes Distress Scale* score was 2.4 (SD 1.1), indicating moderate distress.

## Diabetes distress domains

**Regimen distress.** Veterans described that both following a T2DM self-management routine (e.g. managing diet, self-monitoring blood glucose, engaging in physical activity, maintaining a routine) and deviating from that routine causes distress. For example, they expressed that after receiving a T2DM diagnosis, the need for constant awareness and decision making, particularly around food, was distressing in that it differed from their former routine. As one Veteran explained,

Being diabetic is really frustratin' because you've gotta really be conscious in what you eat. . . . I'm a meat and potatoes guy. I was raised up on bread. . . . I mean, they've limited me on some of the stuff that I really enjoy eating. (V1)

Although Veterans described strategies to manage the impact of their diet on their T2DM, including following dietary restrictions (e.g. restricting refined white flour), creating time windows and routines for eating, and managing recommended food intake, most found these strategies challenging. As one Veteran shared,

I get to the point where, if I only eat one meal a day, it's because sometimes, if I eat something again, . . . it'll shoot my sugar up or . . . down too low. So, now, I [am] afraid to eat at certain times in the afternoon. If I snack, it might be a light snack or somethin' that I know won't shoot my sugar up. . . . I try to just eat one time a day, 'cause half the time, I'm scared to eat. (V2)

Notably, home was mentioned as an important and often preferred location for management of one's T2DM eating plan. Several Veterans expressed that eating at home allowed them to avoid unknown ingredients or tempting foods that could negatively impact their T2DM management.

Monitoring one's blood glucose commonly stood out as a frustrating aspect of the T2DM routine. Veterans described the pain and inconvenience of blood glucose monitoring and reported difficulty with medication use due to the discomfort. One Veteran stated, "The only thing that I really hate about [T2DM self-management] is prickin' my finger. I hate that with a passion" (V3). Some Veterans expressed that testing their blood glucose was tolerable and necessary; however, respondents commonly reported that they desired to use less frequent and painful methods of blood glucose testing, such as continuous glucose monitoring technology (which VHA has not traditionally provided for all Veterans). One Veteran stated,

You get tired of doing [finger stick glucose testing]. And then I see these commercials or whatever [in which] people got these things where they take their phone, and put it to their arm, and get the glucose reading. I mean, why not try that? I mean, who wants to be pricking themselves all the time? (V4)

Veterans desired to engage in physical activity as part of their T2DM self-management routine, but many stated that physical ailments or pain, both independent of, or due to, T2DM, impeded their ability to do so. One Veteran shared, "I have a bad back, for one thing. . . I can't go far before I just get exhausted and feel like I'm lightheaded, and I'm falling all the time. . . I don't do too much physical activities at all" (V5). Several Veterans specifically described service-related injuries that hampered their physical activity. One respondent said, "When I got out of the military . . . both my knees were gone. I got medically discharged. So pretty much since then, . . . it's been an ongoing battle with pain, and everything just seemed to compound" (V6).

Self-management routines did not occur in isolation, and the context within which T2DM self-management occurs is an important consideration. Many Veterans in our sample described their self-management routines as multifaceted, with interdependent steps that often require preparation and situational awareness. For example, a Veteran stated,

I always carry a little glucose in case my sugar drops, which can happen pretty easily. Because if I'm exercising a little bit . . . just having more physical activity such as moving boxes, that can cause my sugar to drop, and if it drops, I get very lightheaded, could pass out, and it really gets very dangerous. (V7)

Other Veterans preferred to stay at home to ensure proximity to their T2DM supplies (e.g. medications and glucose monitors) rather than to leave home to engage in life or social activities. Several Veterans expressed feeling anxious

or fearful of potential short- and long-term consequences of deviating from their routines.

**Emotional distress.** Emotional distress results from, and contributes to, the challenges of T2DM self-management. The inability to adequately self-manage T2DM despite understanding the components and tasks of self-management was a commonly expressed source of frustration and fear. One Veteran clearly described the emotional shifts occasioned by the complexity of living with T2DM:

I have been a big failure at managing diabetes. I've tried to do things, but diabetes is kind of like a catch 22: You do one thing, and then you fail at another. If you exercise like you're supposed to, and manage your diabetic medication like you're supposed to, you end up in this endless routine cycle that seems to work pretty much. But then you end up with this anxiousness . . . that really bothers you a lot, and then you end up with kind of a depression, and it kind of hits you really hard. And so, then you have to try to deal with that, which causes you to go off your meds a little bit, which causes a cycle of breaking your habits of trying to be disciplined. And you go back and forth between anxiety and discipline. It's kind of hard to do, and so you end up . . . in your room, depressed and hiding candy and fudge . . . because you don't want your family members knowing that you're depressed and loading yourself up with sugar. (V7)

Not only did Veterans express feeling frustrated by previous experiences of having struggled with their T2DM self-management, many described significant fear for their future given their T2DM diagnosis. They described fearing the consequences of poorly managed T2DM (e.g. amputations, kidney failure and dialysis, death) which they had observed family and friends experiencing or learned about from clinicians or other sources. Many Veterans specifically noted distress pertaining to the incurable, progressive nature of T2DM and the burden of life-long self-management. One Veteran described their fear and frustration as follows:

Living with [*diabetes*] is just a constant, constant battle, and you know you're not gonna win. Now that's the big thing about it. You know you can't beat this thing. You know it's gonna kill you sooner or later, just a matter of time. Well, like the doctors tell me, if the diabetes won't kill me, something else will kill me that the diabetes has made to stop workin'. So, it's just something you gotta recognize is gonna happen, and you learn to live with it. I could go tomorrow. It's just the way it is. (V8)

The sense of "I could go tomorrow" was shared by other Veterans. One expressed,

My diabetes distress stems from the fact that I feel this [small laugh], it sounds silly, but I feel like this sense of impending doom. Like I may have gone—because you know, you can only punish your body so far before it says, "I'm done. I can't come back from this." So, for me, the diabetic distress is [asking], "Am I at that point where no matter what I do, I can't fix this?" (V9)

However, some Veterans who disclosed their fear of the future also noted that they accepted their diagnosis of T2DM and were resigned to living with the challenges of this disease.

**Interpersonal distress.** Veterans described experiencing interpersonal distress when responding to questions about their T2DM self-management, such as barriers to, and facilitators of, related routines. They also discussed various ways in which their interpersonal relationships had been strained by frustrations arising from perceptions of management during social eating situations. Many highlighted the stress of eating at restaurants and needing or wanting to deviate from their routine diet.

Veterans noted that accommodating T2DM self-management created friction between themselves and others, describing how family and friends altered menus and traditional foods or changed event activities to accommodate their food restrictions and routines. Some described the stress caused by needing time for self-management activities, such as extra breaks

during the workday or family events to handle blood glucose monitoring or insulin injections. One Veteran described the stigma he felt when injecting insulin in public:

It's not like when you take a pill. You can take a pill in a little pill capsule. . . . [but to take an] insulin injection, you have to either take your whole kit with you or already have those syringes set up to take them with you throughout the day. . . . [Y]ou have to pretty much pull out a syringe in front of people or go somewhere and like, secretly take medication . . . [T]hat kind of gets to me. . . . I feel like a drug addict, put it that way—the looking around when they take the shot. (V10)

Many Veterans described occasions on which an accommodation for their T2DM self-management (e.g. insulin injections, food choices) had been made for them; some recalled feeling appreciative while others recalled that such efforts had felt unhelpful or othering.

Physical and mental changes due to T2DM contributed to interpersonal distress for many Veterans. A few respondents shared physical changes, such as frequent urination or erectile dysfunction, had contributed to interpersonal distress. Two Veterans described their difficulties in maintaining romantic relationships with prospective partners. One Veteran shared,

I'm not a partner to nobody yet . . . [because of] what I have, and I can't understand it. At 61 years old, I just can't understand it. . . . I know I'm not right physically, in a relationship. . . . I don't offer myself to anyone because I know I can't do nothing, but I tell 'em about my sickness, and I know they don't wanna hear that. They don't wanna be bothered with me, so I'm learning how to just be myself and go on 'bout my business. (V11)

Similarly, several Veterans described negative emotions (e.g. depression, PTSD) related to T2DM or other comorbidities impacted their ability to engage in and maintain interpersonal relationships.

**Provider distress.** A few Veterans in our sample described experiencing physician or provider distress as part of their DD. Of the five Veterans

who mentioned physician distress, two wanted more access to doctors for support and patient education; both had experienced frequent change of, and adjustment to medications, in order to manage their blood glucose. These Veterans expressed that their distress would have been mitigated had their providers explained why they were discontinuing or prescribing medications. Two other Veterans mentioned communication issues with their providers. One Veteran shared their frustration over a miscommunication about his T2DM diagnosis:

I love my doctor. . . . I feel she really cares about my health. So that's important to me. And she's my VHA doctor, and she's amazing . . . but [for] whatever reason, the last time I went there . . . she did my last blood test, [and] she found out, she's always known, that my sugar was really high, and I was borderline diabetic . . . [but] they had me ran in the system as being diabetic. Type 2 diabetes, non-threatening. And I was like, I didn't even know that. . . . always [before], like, I'm at the edge. I'm at the edge. I'm at the edge. Well apparently, the last time I had a blood test, she entered me in as being diabetic. (V9)

Another Veteran had long been provided with conflicting information about whether they had Type 1 or Type 2 diabetes and reported feeling frustrated and distressed about their uncertain diagnosis and lack of support:

Well, my old doc kinda kept me in the dark. You know, I was put on . . . metformin, and I didn't know what it was for. And then they kept on asking me if I'm diabetic. And I'm like, "Oh I don't know" 'cuz nobody ever said, "You're a diabetic." But they'd check my . . . A1C, you know. That would be, I guess, below the threshold. . . . There's times they check your blood sugar, I'm clueless about. I don't wanna do it. Even the levels . . . I asked "What is low? What is high?" And they're like, "Well, you can just check on the internet for that." I'm like, "Well great." (V6)

Veterans who experienced provider distress wanted more communication from their provider during certain activities as well as a clear statement of their diagnosis and treatment plan.

Additionally, some Veterans expressed distress associated with providers' expectations that the T2DM self-management plan they have specified will be followed. As one Veteran shared,

When I meet with my pharmacist or with my doctor, and they ask me about how am I doing, that's when I be like, "Man, I should've been doin'" a little bit better,' 'cuz you know, it catches up with you. Especially when you go in for a checkup. And they already put everything out before you that you need to do, and I'm not following through on it all, you know, completely. So, it's kinda embarrassing that you have to tell 'em, "No, I didn't follow through on it as talked about." (V12)

### *Additional facets of DD*

*Event-based distress.* As our cognitive interviews on the DDS revealed, event-based distress may contribute to DD in Veterans. Event-based distress describes distress related to an incident (e.g. party, special occasion, holiday) or realization (e.g. loss of ability) that impacts the individual's T2DM or self-management. Many Veterans in our sample described one or more events that caused DD within, across, or independent of existing domains of DD.

Because we conducted our data collection during the COVID-19 pandemic, all Veterans described being impacted by pandemic-related closures. Veterans communicated the impact of pandemic-related unemployment and income loss on their medication and supplies, loneliness due to social isolation, and limited opportunities for physical activity due to closures of gyms and other public areas. Veterans described limited access to health care due to the pandemic. One Veteran explained,

[W]ith COVID, the access to the pharmacy has been tightened because the trips to the VHA has been restricted, and . . . face-to-face appointments with doctors have become more restricted. And because of all of that, I can't get anything done because I can't go in and talk to anybody face-to-face. (V7)

Many Veterans described pandemic-related negative influences on their T2DM self-management routine, including COVID-related memory loss, changes in eating routines due to working from home and restaurant closures, and the need to conserve T2DM medications and supplies due to shortages or delays. Additionally, Veterans described their high risk for complications of COVID-19 due to their T2DM as an independent stressor impacting T2DM self-management.

One commonality of event-based distress across events was the discordance between self-expectations of engagement with their routine and disrupted opportunities for T2DM self-management in particular contexts. Veterans reported that special events such as holidays and other celebrations caused distress as short-term gratification or social expectations conflicted with long-term needs and goals for T2DM self-management. For example, one Veteran described,

I do stress out. When I started on my diet at this time last year, I lost about 30-something pounds. You know, . . . over the wintertime you get into the holidays and stuff. I probably gained about 10 or 12 of it back and [am] trying to manage that. But yes, it is stressful every day when . . . you get around peer pressure, you wanna eat something, or you don't. (V13)

Several Veterans described struggling with relatives and friends around special events. One Veteran stated, "It's hard to stick with [a T2DM diet] when you see Christmas time. They come over with cakes and candy, and they'll ask ya, 'Do you want somethin'?" [and I say,] "Nah, I can't eat it. I have to turn it down" (V14). Holidays can be anticipated and accommodated into one's routine, but unexpected disruptions (e.g. medical emergencies, unplanned socializing) posed challenges to Veterans' self-management routines. As one Veteran described,

I spent five days in the hospital, and it's not like being here at home, controlling everything including my medicines . . . [so] my diabetes got out of control totally. And it took me two or three

weeks to get it back straight to where I got it right now. (V14)

Veterans shared that they experienced distress when they did not know how to manage the impact of a change to their normal routine caused by a special event, social activity, new physical challenge, or unexpected medical event (e.g. hypoglycemic event).

**Pain.** Pain in the context of T2DM is a challenge that impacts disease self-management and engagement in daily activities. Asked about distressing barriers to self-management, Veterans described pain as an important contributor to DD. Over half of the respondents described that pain and physical limitations interfered with their activities of daily life. Veterans described three categories of pain sources that impact self-management of T2DM: (a) biological T2DM processes (e.g. diabetes-related neuropathy), (b) T2DM self-management (e.g. blood glucose testing), and (c) comorbid pain (e.g. migraines, arthritis, military injuries). Discomfort and pain were reported by Veterans, many of whom were experiencing some degree of diabetes-related neuropathy due to their T2DM, as negatively affecting their functioning and independence. One respondent described,

I've got all kinds of issues that come along with diabetes; neuropathy is one of the things that happens. And I've got neuropathy, and my fingers and my toes are all—they feel like they're on fire all the time, and the pins and needles are always attacking my toes and my fingers. My arms and my legs, they feel like somebody's put 'em in a campfire, burning 'em all the time. They just hurt. . . . I don't even wanna walk across the floor 'cause it hurts . . . so I sit. (V7)

Veterans reported pain related to finger-prick blood glucose testing. For some, this pain contributed to an avoidance of blood glucose monitoring, which negatively impacted T2DM management. As one Veteran shared, “That’s the hardest part about this: sticking my finger . . . every day” (V5). Another described that

their willingness to check blood glucose comes and goes: “I mean there are times during the week [when] I just, I get fed up with it. I don’t wanna stick myself, so that morning, I don’t. I just put it in my logbook that I wasn’t feeling well” (V15).

Many Veterans in our sample had comorbid health conditions that caused pain such as osteoarthritis or limb amputations. One Veteran shared,

I have chronic pain every single day, and I told the doctors . . . and they put it on, you know, arthritis in my back, and in my knees, . . . and in my hands. Cause sometimes I’m fine, and then sometimes . . . it hurts to . . . make a fist or even open my hand. I mean, they haven’t give[n] me no medicine for that. . . [T]he pills they give me . . . is supposed to help with arthritis, but it does . . . nothin’ at all. It barely does anything for my migraine pain. But, I mean, all I can do is just tell them what I’m experiencin’ with the medicine, and that’s it. Either they tweak it up a little bit, or they cut back, or they will try me on somethin’ else, and I’m tired of being the test dummy for different medicines. (V2)

Some Veterans described how their pain impacted their sleep or their ability to relax. One Veteran explained,

[T]he nighttime is just, oh God, after 5 or 6 o’clock at night, the pain, “cause that’s when I’m home, and I’m startin’” to relax. And as soon as I start to relax, literally within 10 minutes if I sit in a recliner and I start to relax, bang, everything really just jumps right in there; the restless legs, the leg pain, everything takes off. I’ll start getting shootin’ pains up and down my legs. Things really get bad at night. (V8)

Veterans described how pain disrupted their self-management behaviors by affecting their ability to engage in physical activities, cook T2DM-friendly foods, or monitor their blood glucose regularly. One Veteran stated,

I have back pain, nerve damage, knee, hip [pain]. And it doesn’t always affect me at the same time.

But . . . I could be doing something . . . and I just have to stop, so I try not to do too much as far as anything past walking. No jogging. No running. None of that kind of stuff. No real big physical lifting or anything like that. Unless it's something that I just have to do. So, it's pretty much a light workday, every day. (V9)

Veterans also described pain as a cognitive burden that interferes with self-management and medication use. One Veteran said, "I'm always in pain. You always gotta remember, geez, did I take the pills at this time? . . . I got a pill thing that I keep everything in. Do I have time for this stuff? It's just a constant struggle." (V8) Veterans described the interplay between the cognitive burden and their pain; one Veteran shared that their pain impacts their memory: "If I don't [manage T2DM] . . . like I'm supposed to, then the neuropathy gets worse, which means my feet are on fire. I mean, like walking on rocks and glass" (V17).

*Military experience.* Military experience is a theme that was present across all domains of DD. Several Veterans explained that military basic training and service within the military's organized culture provides a framework for developing structure and following through with routines. Veterans attributed their ability to stick to a routine, engage in self-discipline, and persevere in their T2DM self-management to their military experience and understanding of military culture. As one Veteran stated, "I would say it's all about discipline. . . [T]he number one thing you learn in the military is discipline. . . . [D]iscipline helps me to stay on my routine and my schedule. So, yeah, it's good for me" (V18). Another Veteran expanded on the idea of the military's influence on their T2DM self-management: "You've got to roll with the punches and do what ya gotta do. It's as simple as that. Ya gotta take the good and the bad. I learned that in the military. Everything ain't always gonna run smooth" (V8). One Veteran shared that their military service taught them to persevere through challenges: "I served in both conventional and special operations. They just taught me, you know, you have something that

is in front of you like [diabetes], you just work through it" (V19).

However, two Veterans expressed a belief that their T2DM was attributable to their military service. One Veteran stated,

What ticks me off is I can blame the military for giving [diabetes] to me in the first place. Because [of] the Agent Orange. We traced my family history, the VHA did and I did, to my father, who is 94 years old and still sharp as a tack. We don't have anybody in the entire family history on both sides of the family that's ever had diabetes. And bingo. All of a sudden, I get it. (V8)

Many Veterans shared their appreciation for accessible care at the VHA, the quality of VHA providers, and the VHA's focus on Veteran-specific healthcare. Several noted that their access to quality care within the VHA positively impacted their experience of living with T2DM. As one Veteran described,

I'm very fortunate that I'm able to go to the VHA. You know, I have a son that has issues and [is] worryin' about insurance, and I'll be honest with ya, there are good doctors and clinics and everything out here. But I just feel, what I love about being a Veteran, number one, I love my country. But number two is, the people at the VHA are focused on me. (V1)

Overall, Veterans in our sample noted that their experiences in the military and as Veterans delineated them as a special population requiring the care of Veteran-focused providers and services.

## Discussion

Diabetes distress, a normal and expected psychosocial aspect of living with T2DM, presents in various forms among Veterans. We conducted interviews to describe Veterans' experiences of DD in the context of T2DM self-management. We found that (1) Veterans' challenges with their T2DM self-management routines influenced DD; (2) Veterans experienced DD across a wide range of domains, indicating that clinical

interventions should take a “whole-person” approach; and (3) a Veteran’s military experience may impact how they view T2DM and T2DM self-management.

Veterans described their T2DM self-management routines as complicated, overwhelming, and frustrating. Most Veterans in our sample noted that certain aspects of T2DM routines were more frequently distressing than others. Individuals with DD report diabetes-related physical burdens, health care system distress, and distress with comorbid conditions (Arifin et al., 2020; Berry et al., 2020; Tanenbaum et al., 2013, 2016); this expanded catalog of potential DD domains corresponded with the narratives shared by the Veterans in this study. Similar to the findings on DD in an Indonesian population described in Arifin et al. (2020), Veterans in our study described internal and external factors that impacted their DD and ability to engage in T2DM self-management. In addition, Janevic et al. (2018) described the relationship between pain and DD. Our study supports these findings as several Veterans noted that their pain impacted their DD, highlighting the importance of pain management in diabetes care. Notably, the Veterans in our study described experiencing DD and T2DM self-management challenges, despite access to VHA healthcare, providers, support, and supplies, which suggests that DD may be a universal experience for individuals with T2DM.

Veterans appreciate Veteran-focused healthcare delivery. Undiagnosed and untreated DD may be one factor contributing to poor T2DM self-management among Veterans and leading to poor health outcomes, as demonstrated in other populations including active military (Polonsky et al., 2003). Our current research intentionally foregrounded a Veteran-centered focus in the conceptual, empirical, and analytic phases due to our prior work suggesting that Veterans may experience DD differently than non-Veterans. Doing so enabled our research team to explore Veteran’s perceptions about DD in a Veteran-centered approach. We primarily accomplished this goal by asking our local Veteran Research Engagement Panel (VetREP)

to offer feedback on our semi-structured interview guide that asked questions on DD and T2DM self-management. This panel, comprised of Veterans and Veteran care partners, provides feedback to researchers on their study design and approach, including data collection methods, interpretation of findings, and dissemination. VetREP members suggested changes to our approach related to asking Veterans about DD and the wording of questions about obtaining healthcare at VHA, self-managing T2DM, and experiencing DD. After the VetREP consultation, we amended our approach in two ways. First, the qualitative analyst who conducted the interviews used a trauma-informed style of interviewing. The analyst was conscientious in her approach and question-asking style to avoid eliciting a trauma response. Prior to the first interview, the study team reviewed the study protocol on steps to take if a Veteran were to experience a trauma response during or following the interview. Second, the study team reworded several interview questions to improve clarity and understanding.

Veterans in our sample noted the important impacts, both positive and negative, that their military experience and eligibility for VHA care had on their DD and self-management of T2DM; these influences crossed many of the DD domains and other aspects of life with T2DM. For example, Veterans described how their military experiences helped them to create a useful mindset and routine for managing T2DM. Our findings support research on the shared experience of being in the military, and the camaraderie and respect for other Veterans that may result from these experiences (DiNardo et al., 2020; Lafferty et al., 2022; Siple et al., 2015). Similar to the findings in Siple et al. (2015), two Veterans in our sample considered their diabetes diagnosis to result from their military service.

There are several research and clinical implications of these findings. First, our findings support that screening, monitoring, and referral for psychosocial well-being, such as DD, as well as for the social determinants of health, should routinely occur (ElSayed et al., 2023; Owens-Gary et al., 2019). Second, researchers

and clinicians should acknowledge the ways in which military protocol, routine, and perseverance can potentially support Veterans; however, researchers and clinicians must simultaneously appreciate that an evidence-based approach that works for some Veterans may not work for all Veterans. For instance, exercise and physical activity are common parts of the T2DM routine which may be particularly difficult for Veterans for whom overseas deployments, combat operations, and service-related trauma have resulted in physical injury, pain, and illnesses unrelated to their T2DM (Betancourt et al., 2021). Third, one important research implication is that researchers who desire to conduct Veteran-centered research should work with Veteran research engagement panels, which are now broadly accessible within the VHA to help ensure that VHA-funded research is significant and relevant to Veterans and Veteran care partners (Maxwell et al., 2022; Wendleton et al., 2023). Collectively, our findings support using a whole-person approach that strengthens the Veteran's coping abilities for living with T2DM and has the potential to improve outcomes for patients with T2DM while potentially reducing the burden on the healthcare system.

### **Limitations**

This study has several limitations. First, we conducted our study on DD during the COVID-19 pandemic. Veterans may have been experiencing distress related to the pandemic which might have impacted their DD and T2DM self-management. In addition, the COVID-19 pandemic likely impacted their T2DM self-management because many self-management activities were changed or halted. Second, our sample consisted primarily of male Veterans, with a mean age of 59.1 years. Future research should obtain the perceptions of DD of a more diverse (in terms of race/ethnicity, age, gender/sexual orientation, military service era) sample of Veterans as their experiences of DD may differ from those of our sample. Third, the Veterans in our sample all obtained care from one healthcare system and the sample of Veterans was not balanced by clinics type (e.g. primary care,

endocrinology). Future research should sample Veterans from multiple healthcare systems, clinic types, and providers. Despite these limitations, this study adds to the literature on DD in Veterans with T2DM.

### **Conclusion**

A Veteran's military experience may appreciably impact their engagement in T2DM self-management. A full understanding of Veterans' experiences of DD requires that their distress be explored and addressed in additional cognitive, physical, and affective domains. Findings can inform the development of T2DM self-management interventions that provide individually tailored information and services to Veterans with T2DM. Behavioral scientists and clinicians should consider a Veteran's military experience and pain/comorbidities as influences on DD when planning and delivering health care.

### **Authors' contributions**

AAL conceptualized the grant, obtained funding, and wrote the manuscript; MJC, EM, PT, SB, ASJ, CJC, TH, and HBB assisted with grant and protocol conceptualization, study activities, and manuscript editing. AS, CW, JRJ assisted with manuscript conceptualization, editing, and study activities.

### **Acknowledgements**

The authors thank Marilyn Oermann, PhD, and Donnalee Frega, PhD for editorial assistance.

### **Data sharing statement**

We are unable to sufficiently deidentify these qualitative data due to the sensitive nature of this qualitative project. Therefore, we are unable to share these data.

### **Declaration of conflicting interests**

The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Dr. Bosworth reports research funding through his institution from BeBetter Therapeutics, Boehringer Ingelheim, Esperion, Improved Patient Outcomes, Merck, NHLBI, Novo Nordisk, Otsuka, Sanofi, VA. Elton John Foundation, Hilton foundation, Pfizer. He also

provides consulting services for Abbott, Esperion, Imatar, Novartis, Sanofi, Vidya, Walmart, WebMD. He was also on the board of directors of Preventic Diagnostics. Dr. Lewinski reports receiving funds from PhRMA Foundation and Otsuka for activities not related to this work. The remaining authors have no competing interests to declare.

## Funding


The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The research reported in this publication was supported by Durham Center of Innovation to Accelerate Discovery and Practice Transformation grant #CIN 13-410 and VA HSR&D grants #18-234 (to AAL) and #08-027 (to HBB) and the Durham VA Quality Scholars Program OAA #AF-3Q-05-2019-C (to JRJ). The content is solely the responsibility of the authors and does not reflect the position or policy of Duke University, the University of Massachusetts Boston, the US Department of Veterans Affairs, or the US government.

## Ethics approval and consent to participate

The Durham Veterans Affairs Institutional Review Board approved all activities in the proposed research (Protocol # 02284).

## ORCID iDs

Allison A Lewinski  <https://orcid.org/0000-0002-1356-1857>

Abigail Shapiro  <https://orcid.org/0000-0003-3276-0824>

## References

- Adriaanse MC, Pouwer F, Dekker JM, et al. (2008) Diabetes-related symptom distress in association with glucose metabolism and comorbidity: The Hoorn study. *Diabetes Care* 31(12): 2268–2270.
- Ahola AJ and Groop PH (2013) Barriers to self-management of diabetes. *Diabetic Medicine* 30(4): 413–420.
- Aikens JE, Zivin K, Trivedi R, et al. (2014) Diabetes self-management support using mHealth and enhanced informal caregiving. *Journal of Diabetes and Its Complications* 28(2): 171–176.
- Arifin B, Probandari A, Purba AKR, et al. (2020) Diabetes is a gift from god' a qualitative study coping with diabetes distress by Indonesian outpatients. *Quality of Life Research* 29(1): 109–125.
- Berry E, Davies M and Dempster M (2020) Exploring the perceptions of emotional distress among couples living with type 2 diabetes and among diabetes healthcare providers, and consideration of support needs. *Diabetic Medicine* 37(10): 1669–1678.
- Berry E, Lockhart S, Davies M, et al. (2015) Diabetes distress: Understanding the hidden struggles of living with diabetes and exploring intervention strategies. *Postgraduate Medical Journal* 91(1075): 278–283.
- Betancourt JA, Granados PS, Pacheco GJ, et al. (2021) Exploring health outcomes for U.S. veterans compared to non-veterans from 2003 to 2019. *Healthcare* 9(5): 604.
- Bokhour BG, Hyde J, Kligler B, et al. (2022) From patient outcomes to system change: Evaluating the impact of VHA's implementation of the whole health system of Care. *Health Services Research* 57(S1): 53–65.
- Carper MM, Traeger L, Gonzalez JS, et al. (2014) The differential associations of depression and diabetes distress with quality of life domains in type 2 diabetes. *Journal of Behavioral Medicine* 37(3): 501–510.
- Centers for Disease Control and Prevention (2023) *National Diabetes Statistics Report: Estimates of Diabetes and Its Burden in the United States*. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention.
- Chew B-H, Vos RC, Pouwer F, et al. (2018) The associations between diabetes distress and self-efficacy, medication adherence, self-care activities and disease control depend on the way diabetes distress is measured: Comparing the DDS-17, DDS-2 and the PAID-5. *Diabetes Research and Clinical Practice* 142: 74–84.
- Creswell J (2014) *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. Thousand Oaks, CA: Sage Publications.
- Creswell J and Plano Clark V (2011) *Designing & Conducting Mixed Methods Research*. Thousand Oaks, CA: Sage.
- Dennick K, Sturt J and Speight J (2017) What is diabetes distress and how can we measure it? A

- narrative review and conceptual model. *Journal of Diabetes and Its Complications* 31(5): 898–911.
- DiNardo MM, Phares AD, Jones HE, et al. (2020) Veterans' experiences with diabetes: A qualitative analysis. *Diabetes Educator* 46(6): 607–616.
- Drabble L, Trocki KF, Salcedo B, et al. (2016) Conducting qualitative interviews by telephone: Lessons learned from a study of alcohol use among sexual minority and heterosexual women. *Qualitative Social Work* 15(1): 118–133.
- ElSayed NA, Aleppo G, Aroda VR, et al. (2023) 5. Facilitating positive health behaviors and well-being to improve health outcomes: Standards of care in diabetes-2023. *Diabetes Care* 46(Supple 1): S68–S96.
- Fisher L, Hessler D, Glasgow RE, et al. (2013) REDEEM: A pragmatic trial to reduce diabetes distress. *Diabetes Care* 36(9): 2551–2558.
- Fisher L, Hessler DM, Polonsky WH, et al. (2012) When is diabetes distress clinically meaningful?: Establishing cut points for the diabetes distress scale. *Diabetes Care* 35(2): 259–264.
- Guest G, MacQueen KM and Namey EE (2012) *Applied Thematic Analysis*. Los Angeles, CA: Sage Publications.
- Janevic M, Nwankwo R, Funnell M, et al. (2018) Pain interference is associated with diabetes distress in a sample of african american older adults. *Journal of Pain* 19(3): S35.
- Lafferty M, Strange W, Kaboli P, et al. (2022) Patient sense of belonging in the veterans health administration: A qualitative study of appointment attendance and Patient Engagement. *Medical Care* 60(9): 726–732.
- Laranjo L, Neves AL, Costa A, et al. (2015) Facilitators, barriers and expectations in the self-management of type 2 diabetes—a qualitative study from Portugal. *European Journal of General Practice* 21(2): 103–110.
- Lewinski AA, Shapiro A, Bosworth HB, et al. (2021) Veterans' interpretation of diabetes distress in diabetes self-management: Findings from cognitive interviews. *The Science of Diabetes Self-Management and Care* 47(5): 391–403.
- Malterud K, Siersma VD and Guassora AD (2016) Sample size in qualitative interview studies: Guided by Information Power. *Qualitative Health Research* 26(13): 1753–1760.
- Maxwell HL, Smith-Benson PA, Velasquez B, et al. (2022) The importance of the veteran's voice: Three veterans recount their engagement with VA research: Importance of veteran voice. *Journal of General Internal Medicine* 37(Suppl 1): 88–90.
- Owens-Gary MD, Zhang X, Jawanda S, et al. (2019) The importance of addressing depression and diabetes distress in adults with type 2 diabetes. *Journal of General Internal Medicine* 34(2): 320–324.
- Perrin NE, Davies MJ, Robertson N, et al. (2017) The prevalence of diabetes-specific emotional distress in people with type 2 diabetes: A systematic review and meta-analysis. *Diabetic Medicine* 34: 1508–1520.
- Polonsky WH, Earles J, Smith S, et al. (2003) Integrating medical management with diabetes self-management training: A randomized control trial of the diabetes outpatient intensive treatment program. *Diabetes Care* 26(11): 3048–3053.
- Sandelowski M (1995) Qualitative analysis: What it is and how to begin. *Research in Nursing & Health* 18(4): 371–375.
- Sandelowski M (2000) Whatever happened to qualitative description? *Research in Nursing & Health* 23(4): 334–340.
- Sandelowski M (2010) What's in a name? Qualitative description revisited. *Research in Nursing & Health* 33(1): 77–84.
- Siple J, Harris EA, Morey JM, et al. (2015) Experiences of veterans with diabetes from shared medical appointments. *Federal Practitioner* 32(5): 40–45.
- Sturt J, Dennick K, Hessler D, et al. (2015) Effective interventions for reducing diabetes distress: Systematic review and meta-analysis. *International Diabetes Nursing* 12(2): 40–55.
- Tanenbaum ML, Kane NS, Kenowitz J, et al. (2016) Diabetes distress from the patient's perspective: Qualitative themes and treatment regimen differences among adults with type 2 diabetes. *Journal of Diabetes and Its Complications* 30(6): 1060–1068.
- Tanenbaum ML, Ritholz MD, Binko DH, et al. (2013) Probing for depression and finding diabetes: A mixed-methods analysis of depression interviews with adults treated for type 2 diabetes. *Journal of Affective Disorders* 150(2): 533–539.

- Vespa J (2020) *Those who served: America's veterans from world war ii to the war on terror*. Reports ACS. Washington, DC: U.S. Census Bureau.
- Veterans Health Administration (2016) *VA Research on Diabetes*. Atlanta, GA: U.S. Department of Veterans Affairs, Veterans Health Administration, Office of Research and Development.
- Veterans Health Administration (2023) *Veterans health administration: About VHA*. Available at: <https://www.va.gov/health/aboutvha.asp> (accessed July 16).
- Wendleton LR, Martin LA, Stewart Steffensmeier KR, et al. (2023) Building sustainable models of veteran-engaged health services research. *Journal of Humanistic Psychology* 63(6): 874.