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Authors

Hernandez, Lenore Leutwyler, Heather Swislocki, Arthur <u>et al.</u>

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The Symptom Experience of Older Adults with Type 2 Diabetes and Diabetes-related Distress

Lenore Hernandez, PhD, RN, CNS

Department of Family Health Care Nursing, University of California San Francisco, Medical Service, Veteran's Affairs Northern California Health Care System

Heather Leutwyler, PhD, RN, NP, CNS, Janine Cataldo, PhD, RN

Department of Physiological Nursing, University of California San Francisco

Alka Kanaya, MD,

School of Medicine, University of California San Francisco

Arthur Swislocki, MD,

Medical Service, Veteran's Affairs Northern California Health Care System and Division of Endocrinology, Department of Internal Medicine, University of California Davis School of Medicine

Catherine Chesla, PhD, RN

Department of Family Health Care Nursing, University of California San Francisco

Abstract

Background: An older, more diverse population and longer lifespans are major contributors to the anticipated tripling of type 2 diabetes prevalence by 2050. Diabetes-related distress affects up

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Corresponding author: Lenore Hernandez PhD RN, 1018 Hampton Drive, Concord, CA 94518; Lenore.Hernandez@va.gov. Lenore Hernandez, PhD, RN, CNS is a graduate of the University of California San Francisco, Department of Family Health Care Nursing and works for the Medical Service, Veteran's Affairs Northern California Health Care System as a Clinical Nurse Specialist in Diabetes

Heather Leutwyler, PhD, RN, NP is a professor at the University of California San Francisco, School of Nursing-Department of Physiological Nursing, specializes in the care of older adults with schizophrenia and is a fellow of the Gerontological Society of America

Janine Cataldo, PhD, RN, CNS is a professor and department chair at the University of California San Francisco, School of Nursing-Department of Physiological Nursing/Gerontology/Oncology, Associate Director at the John A. Hartford Center of Geriatric Nursing Excellence, School of Nursing, University of California, San Francisco, and Core Faculty for University of California Center for Tobacco Control Research and Education

Alka Kanaya, MD is a professor at the University of California San Francisco, School of Medicine, Epidemiology and Biostatistics and a General Internist at the University of California San Francisco Medical Clinics, specializes on clinical research in the field of type 2 diabetes and Obesity

Arthur Swislocki, MD is an endocrinologist at the Martinez Veteran's Healthcare Administration in Martinez, California and at the Veteran's Healthcare Administration clinic in Mather Airforce Base in Sacramento, California, also a professor at the University of California Davis School of Medicine.

Catherine Chesla, PhD, RN is a professor at the University of California San Francisco, School of Nursing-Family Healthcare Nursing Department, a fellow with the American Academy of Nursing, a Thelma Shobe Endowed Chair in Ethics and Spirituality, awarded a distinguished contributor to Family Nursing Research by the International Family Nursing Conference, and awarded Excellence in Teaching—Research Mentorship by the University of California San Francisco School of Nursing and the Helen Nahm Research Lecturer Award by the University of California San Francisco

Ethical Conduct of Research: Highest ethical standards were followed during the process – the project was approved by the IRB at the University of California San Francisco and the IRB at the Veteran's Health Care Administration. Each person signed an IRB approved release and each interview took place in a private location.

The institutional review board (IRB) at the University of California San Francisco and the IRB at the Veteran's Health Care Administration approved the project. Each person signed an IRB approved release and each interview took place in a private location.

to 40% of people diagnosed with type 2 diabetes, and may be a greater risk for older adults due to greater prevalence of comorbidities.

Objective: The objective of this phenomenological study was to describe how diabetes-related distress in older adults (65 years) with type 2 diabetes might be uniquely experienced.

Methods: Participants were recruited using convenience sampling and snowball sampling. Interpretive phenomenology guided the research design and analysis. With interpretive interviews, we investigated the everyday health, symptoms, and life experiences of living with type 2 diabetes and elevated diabetes distress.

Results: Among the older adults in this study, the most prevalent symptoms were fatigue, hypoglycemia, diarrhea, pain, loss of balance, and falling. These diabetes-related symptoms led to substantial loss of independence, decreased quality of life, and constrained social lives due to restricted activities.

Discussion: Diabetes-related distress presents with some unique symptoms and responses in older adults. Improving knowledge regarding the symptom experience of older adults with diabetes-related distress may allow healthcare providers to tailor treatment and thus improve outcomes for older adults struggling with diabetes.

Keywords

diabetes-related distress; older adult; symptoms; type 2 diabetes

Among healthcare challenges in the United States, the epidemic of type 2 diabetes is a leading concern—affecting over 30.3 million people—which represents 9.4% of the population (Centers for Disease Control [CDC], 2017). Moreover, the prevalence of type 2 diabetes shows no sign of abating; by 2050, the proportion of people in the U.S. with type 2 diabetes is projected to triple (American Diabetes Association [ADA], 2015). Leading factors in the growth of the diabetes epidemic are an older, more diverse population and longer lifespans (ADA, 2015).

Older adults with type 2 diabetes versus younger adults have higher mortality, reduced functional status, and an increased risk of institutionalization (Kirkman et al., 2012). Older adults versus younger adults with type 2 diabetes also have a greater prevalence of comorbidities; older adults may be at a greater risk for developing diabetes-related distress. Worry, frustration, and burnout characterize diabetes-related distress, which results from the unique emotional burdens of living with diabetes (Gebel, 2013). These emotions associated with diabetes-related distress are often related to concerns about getting proper treatment or communicating with healthcare providers (Gebel, 2013). In this regard, diabetes-related distress is a predictable emotional response to adverse or unpleasant stressors (Snoek, Bremmer, & Hermanns, 2015) and to the threat of a life-changing illness (Gebel, 2013). This affective state affects as many as 40% of people diagnosed with diabetes and has been shown to increase in symptomatic severity over time (Berry, Lockhart, Davies, Lindsay, & Dempster, 2015; Lipscombe, Burns, & Schmitz, 2015). Indeed, the emotional adjustment to the daily demands of diabetes management can be physically and psychologically draining (Tanebaum, Kane, Kenowitz, & Gonzalez, 2016), and diabetes-related distress is in some

cases concurrent with depression. Previous research has shown that based on depression assessment tools, what appears to be depression, may be a reflection of general emotions related to diabetes-related distress (Fisher et al., 2007). Therefore, interventions for distressed, but not clinically depressed, diabetic patients may be more beneficial.

Researchers have hypothesized that diabetes-related distress is a barrier to effective blood sugar control and increases the likelihood of diabetes-related complications (Berry et al., 2015; Gebel, 2013). There is evidence that people with type 2 diabetes who are experiencing diabetes-related distress may be less likely to take medications to lower blood glucose and, consequently, may be more likely to have hyperglycemia (Gebel, 2013). Diabetes-related distress and elevated HgbA1c are also strongly correlated (Berry et al., 2015).

Researchers have suggested that in older adults with diabetes, symptoms such as fatigue, hypoglycemia, and neuropathic pain contributed to diabetes-related distress (Berry et al., 2015; Browne, Ventura, Mosely, & Speight, 2013; Fisher et. al., 2010; Kirk et al., 2015; Maderson & Kokanovic, 2009; McMahon, Fonda, Gomes, Alexis, & Conlin, 2012; Nicolucci et al., 2015; Park, Park, Quinn, & Fritschi, 2015; Stuckey et al., 2014). However, a focused examination of the symptom experience of this population has not been conducted. The aim of this study was to identify symptoms and co-occurring symptoms that are particular to older adults with type 2 diabetes and elevated diabetes-related distress from the participants' perspectives. The long-term aim is to identify clinical treatment approaches that might more successfully address the unique difficulties experienced by old adults in their diabetes self-care.

Methods

Design and Methods

Interpretive phenomenological methodology guided the research design and method (Benner, 1994). Interpretive phenomenology is a qualitative method that investigates detailed narratives of situated actions and concerns that drive that action. The primary focus is the participant's lived experience and the meaning that she/he makes of that experience (Smith, Flowers, & Larkin, 2009). The lived experience is understood through the voice of the participants' narratives and reflections that encompass their embodiment and situated understanding of the world. Interpretive phenomenology provides access to the commonalities and differences in the experiences of those similarly situated (Benner, 1994). Other forms of phenomenology are more descriptive of the human experience and embrace neutrality while interpretive phenomenology aims to gain insight into how a given person, in a given context, makes sense of a given phenomenon (Lopez & Willis, 2004).

We used interpretive interviews to investigate the everyday health and life experiences of being an older adult with type 2 diabetes. Interpretive interviews employed narrative and reflexive questions. Narrative questions focused on direct concrete experiences with diabetes and its care, while reflexive questions focused on respondents' thoughts about or reflections on the whole of their experiences with types 2 diabetes. The interview guide is in Table 1. Narrative questions (i.e., questions 2–4) allow entrée into participants' experiences that are directly and unreflectively experienced. Reflexive questions involve thinking back and

summarizing an experience (Shaw, 2016). Reflexivity is essential in interpretive phenomenology and facilitates the awareness between the researcher and the participant (Shaw, 2016). After transcription, we read and reread interview to ensure accuracy (Benner, 1994). Interviews focused on the sequela of diabetes, the influence of type 2 diabetes on daily lives, feeling and thought processes.

Sample

We sampled individuals diagnosed with type 2 diabetes aged 65 and older because this is when Medicare benefits can be initiated (Social Security Administration, 2018) and medical treatment of the elderly (geriatrics) starts from the age of 65 (Sieber, 2007). Additional inclusion criteria included persons with moderate or greater diabetes-related distress. We used the Diabetes Distress Scale (DDS) to measures diabetes-related distress. The DDS is a 17-item scale that assesses four dimensions of distress: emotional burden, regimen distress, interpersonal distress, and distress with physician (Behavioral Diabetes Institute, n.d.; Fisher, Glasgow, Mullan, Skaff, & Polonsky, 2008; Polonsky et al., 2005). An overall score of three or greater on the DDS indicates moderate or greater level of diabetes-related distress (Behavior Diabetes Institute, n.d.). The overall scale has demonstrated good internal consistency (Cronbach's alpha = .9) (Behavioral Diabetes Institute, n.d.). Exclusion criteria for the sample included conditions that precluded participation in open-ended interviews.

A convenience sample was recruited by flyers that were posted at local senior community centers in Contra Costa County, CA (n = 8; number of participants recruited from senior centers) and through snowball sampling (n = 3). Additional participants were recruited at a Veteran's Administration Northern California Health Care System (VANCHCS) site in Martinez, CA, where the first author, a certified diabetes educator, invited participation for persons meeting the study criteria (n = 5). Potential participants were screened in-person or by phone to confirm their age, diagnosis, diabetes-related distress level, and willingness to participate in two interviews that would last 1–2 hours each.

Data Collection

Data collection included two one-on-one interviews that were audio recorded and then transcribed, a demographic questionnaire, and the Patient Health Questionnaire-9 (PHQ-9) (Table 3) to assess depressive symptoms. We designed open-ended interview questions using symptom management theory (SMT). SMT proposes that symptom management has three interrelated dimensions: symptom experience, symptom management strategies, and symptom status outcomes (University of California, San Francisco School of Nursing Symptom Management Faculty Group, 1994). Guided by SMT, participants were asked specifically (Table 1) about how diabetes interfered with their ability to take care of things that are important to them, their capacity to interact with family and friends, their management of diabetes in partnership with their primary care provider, and feelings in their body that they interpreted as being due to diabetes. As well, we asked participants to provide narratives about their experiences living with and caring for their type 2 diabetes that were both positive and negative.

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At the end of the first interview, participants completed the PHQ-9 depression scale to determine whether, in addition to diabetes-related distress, participants had depression. The PHQ-9 is a 9-item depression scale based on the nine diagnostic criteria for major depressive disorder (Cronbach's alpha = .89 [Kroenke, Spitzer, & Williams, 2001]; (r= .790) [Zhang et al., 2013]) (Table 3). We also asked participants to complete a demographic questionnaire (Table 4) that included self-reported diabetes-related complications and a daily pill count of prescribed medications.

Throughout the interview process, attention was paid to rigor by (a) offering and checking on interpretation to confirm understanding of the participant's experience; (b) taking detailed notes on the participant's nonverbal communication, appearance, and environment; and (c) recording detailed reflections and perceptions on the experiences, influences, and feelings of the first author. This process augmented the study's validity (Benner, 1994; Smith et al., 2009). The study was approved by the IRB at the University of California, San Francisco and the IRB at the VA in Northern California. Sixteen participants completed a signed written consent and received \$25 in cash or as a gift card after each interview.

Data Analysis

We conducted narrative and thematic analyses using the transcribed text of the interviews. We analyzed each narrative for the difficulties it presented, the resources available to address difficulties, concerns expressed, and the outcome (Benner, 1994). We initially reviewed reflexive text using open coding and from this coded text, identified themes. We used the Atlas-ti software program to manage analysis. Five frequently appearing codes were specific to symptoms and diabetes management challenges; we examined the complete text from these symptom codes together. We used analyzed narratives to enrich understanding of the themes. With over 300 pages of text, the analysis involved a complete review of the daily life experiences and symptoms as described by all participants. Commonalities and differences in participants' experiences were highlighted throughout the analysis. For each participant, we conducted the analysis with an awareness of their living situation, complications, length of diagnosis, and emotional reactions. Field notes compiled during the interviews were complementary sources of information to facilitate the process.

Results

Sample

Sixteen individuals participated in this study: 7 men and 9 women. In this sample, women were older than men (81.5 + 3.5 vs. 68.8 ± 3.1 years, p < .001). Nine of the participants were widowed or divorced; six were married and one was never married (Table 2). Most participants were White (Table 2).

Men in this study were more likely to experience depression than women (PHQ-9 scores 9.5 \pm 2.1, 4.8 \pm 1.2, p < .001). Also, men from the VANCHCS sample had higher scores on the PHQ-9 than the men in the community sample (13.6 \pm 7.2, respectively). The groups did not differ in DDS scores. Women were diagnosed with diabetes for a longer period than men (17 \pm 18 and 11 \pm 16.11 years, respectively). Men were more likely to require insulin for blood

sugar control. Neuropathy, the most frequently self-reported complication, was more often reported by men.

Symptom Burden

This sample of older adults with type 2 diabetes and diabetes distress reported substantial symptom burden. Symptoms most frequently reported were fatigue, hypoglycemia, diarrhea, pain, and loss of balance and falling. Participants' experiences of symptoms are presented in order of descending frequency.

Fatigue.—Twelve participants described being tired or fatigued. For many, disrupted sleep patterns exacerbated tiredness and fatigue. Many of the participants who reported that they were unable to complete tasks and described this in terms of "laziness." They were frustrated with this inability, as one of them attested:

"The fatigue is just overwhelming. If I want to clean the house or something, I have to take the little energy bottles, so that I have enough to get through a room. It's so hard to explain, but it's like being sick with the flu. Your body just aches and is just worn out just from waking up."

For participants who lived with partners, this inability to complete tasks caused disruption, tension, and quarrels. Some participants said that their partners did not appear to understand that their sedentary behavior and fatigue were a symptom of diabetes. For participants who did not live with partners, the fatigue was overwhelming.

For many, their symptoms of fatigue and tiredness inhibited engagement in physical activity and increased engagement in sedentary behaviors, such as watching television and reading. For some participants, at various times, blood sugar elevations, chronic pain, or lack of sleep, resulted from the strain of coping with both diabetes and comorbidities and precipitated fatigue and tiredness.

Hypoglycemia.—Ten of the participants reported symptoms of hypoglycemia. Efforts at improving blood sugar control, increasing the intensity of blood sugar lowering medications, and eating lighter meals (or skipping meals) increased the likelihood of experiencing hypoglycemia. Some participants reported severe incidents of hypoglycemia that led to falls and decreased level of consciousness but even moderate incidents of hypoglycemia, were remarkable to participants. One participant described these symptoms in graphic terms:

"I thought I was going to die. Literally I thought it was so painful in my head that I thought I was going to lose it. I had to sit down in this shop and they rang for an ambulance for me."

Hypoglycemic events, described as traumatic and scary, increased a sense of vulnerability. Participants reported that being older with type 2 diabetes, suffering from pain, having balance and falling problems, and being constrained to sedentary behaviors, heightened their sense of vulnerability. This was particularly true for those who lived alone.

Diarrhea.—Eight of the participants experienced diarrhea and noted that the frequency and socially embarrassing features of diarrhea negatively affected their quality of life (QoL).

One participant described her diarrhea as occurring at least six times throughout the day. Gastrointestinal symptoms interfered with the ability to engage in community activities and many participants described searching for bathrooms ahead of time when they ventured outside of their homes and anticipated incontinence. "If I had the feeling that I got to go to the bathroom, well I was too late. I have left shorts in all the bathrooms all over California."

One of the participants said the frequency of diarrhea interfered with his work. Not wanting to disclose his condition to his supervisor, he tried to time his bathroom breaks to coincide his supervisor's lunch hour. Some of the participants indicated that they took Imodium (Loperamide) frequently; some also wore incontinence pads.

Some of the participants disclosed during the interviews that they felt the metformin they were prescribed was the cause of their diarrhea. Healthcare providers continued to increase the metformin dosage despite objections from the participants because of their gastrointestinal symptoms.

"My healthcare provider [*sic*] would say, 'We're going to give you four in the morning.'

I'd say, 'No, you don't understand. I have explosive diarrhea. Not just loose stool.

I really have problems with it.""

Participants also self-modified their metformin dosing. One participant said:

"Yeah, I had a lot of problem with that when I was at [a healthcare organization].

The healthcare provider [*sic*] tried to get me on four tablets in the morning. I would have terrible diarrhea, so I cut back to two because I was okay on two pills but when I went to four pills, it was really bad."

Another participant spoke about his diarrhea with his healthcare provider who corrected the problem by prescribing an antidiarrheal medication. The provider did so without checking to see if the patient was taking metformin.

One participant described that the potential for diarrhea as a cause of anxiety:

"I would always have it on my mind, like when is it going to get to me? You know?" Another participant had a similar emotional response: "Yeah. It is frustrating and it's disappointing. I like to do these things. It's like, 'Oh, please. I don't have time for this. I don't have time to be sick." Participants noted that having diarrhea at inopportune times made participating in outdoor activities, such as walking, challenging and increased their tendency to stay home and watch television or read.

Pain.—Seven participants reported that they have neuropathic pain and described it as "tingling," "burning," "numbness," "aches and pains like the flu." Participants described other neuropathic symptoms as "crawling" sensations on their lower extremities such as feelings of "electricity" or "bugs." Many described sensations of "walking on cobblestones," "thick calluses on your fingertips and toes," "a squeezing sensation in the feet," or of "wearing shoes when lying in bed." For some participants, pain and discomfort was more

pronounced at night, disrupting their sleep. Many of the participants were taking pain medication as part of their treatment regimen but the medication did not resolve the pain.

Loss of Balance and Falling.—Four of the participants experienced a loss of balance and falling, diminished safety and limited ambulation, making exercise difficult. In describing his experience of loss of balance, one of the participants noted:

"I have to use hand rails to the stairs. That's a must. Or [my girlfriend's] shoulder. Getting up too fast, just have to sit right back down. Turning one direction and other when a doctor wants me to turn your head and forget it. You're shaking up like a snow globe. That's the way your mind feels, like a snow globe. A lot of times to get your balance, to get your thoughts. Just to regain one's self. I just have to pause and wait for the clarity, be it the balance or dizziness, the lightheadedness, whatever. You just wait for that snow globe to settle down."

Another participant moved to an assisted living environment because of her falling history. She described a recent fall outside of her home:

"I've had some falls. In June, I had a pretty serious one. I tripped on a bump in a parking lot after a restaurant visit and hit my forehead without using my hands to stop the fall. Because of the Plavix, I was bleeding everywhere and so we called the ambulance."

Many experienced falling inside or outside the home. One of the participants recounted an experience of falling at her physical therapy appointment:

"She [referring to physical therapist] stabilized me and everything was fine. I walked out and just by the door, I fell down. I got very dizzy suddenly. There was nothing to grab onto and boy do I go down." Falling often occurred quickly and with no warning: "It's amazing how fast you go down. It just came and down I went. There's no advance warning."

Some participants believed that their medications caused dizziness; one indicated he needed to have items arranged around him as a routine to decrease clutter and his risk of falling any of the participants became fearful of ambulation because of their experiences with falling and lack of balance. Pain and neuropathy also contributed to balance issues and walking on rocky or uneven surfaces increased the risk of falling.

Discussion

The aim of this study was to identify from the participants' perspectives and symptoms that are particular to older adults with type 2 diabetes and elevated diabetes-related distress. Among this group, the most prevalent symptoms were fatigue, hypoglycemia, diarrhea, pain, loss of balance, and falling. Because of these diabetes-related symptoms, participants experienced substantial loss of independence, decreased QoL, and a constrained social life due to restricted activities.

Fatigue negatively affected the daily capacity of participants to engage in activities leading to personal frustration and strained interpersonal relationships. Previous research on adults

with type 2 diabetes has shown significant correlations among fatigue, depression, diabetes symptoms, and diabetes-related distress (Park et al., 2015). The participants in this study indicated that pain, fear of falling, and diarrhea influenced fatigue; these combined symptoms may have increased participants' risk for loss for independence and contributed to their diabetes-related distress.

Another factor to consider regarding fatigue, are the potential side effects of medications used for the treatment of neuropathic pain. Although it is not clear what medications participants in this study were prescribed, gabapentin, for example, is an effective treatment for neuropathic pain but may cause fatigue, increase the risk of imbalance, bone loss, falls and fractures—most notably in older adults (Honamand, Safavi, & Zare, 2011). This study adds to the existing body of knowledge on fatigue by clarifying how fatigue interferes with ambulation, increases the risk and fear of falling, promotes sedentary behaviors, and potentially results in challenges with blood sugar control.

Diarrhea symptoms prevented engagement in activities inside and outside of the home, were embarrassing and frustrating, and increased participants' tendency to stay home rather than venture out for shopping or social activities in public. Some participants attributed metformin use as contributing to diarrhea, and some older adults in this study were selfadjusting their doses or omitting the medication because of the diarrhea. Such medication self-management likely resulted in an increase in blood sugars from insufficient medication. Limiting activities outside of the home out of fear of incontinence contributed to a decrease in the overall fitness of some patients. It is unclear why healthcare providers offered metformin only in the standard form rather than in a time-released form. Perhaps some formularies do not include the time-released form, or providers were concerned about the higher cost. It is possible some healthcare providers complicated treatment regimens by adding antidiarrheal medications or by not addressing the diarrhea symptoms with participants.

Metformin is the first line therapy, along with lifestyle modification for most people with type 2 diabetes, as recommended by multiple international guidelines (Bonnet & Scheen, 2017). The mechanisms of gastrointestinal intolerance associated with metformin use is poorly known, but comorbidities, genotype variabilities, and polypharmacy are considered contributing factors to metformin tolerance (Bonnet & Scheen, 2017). Older adults prescribed metformin are at greater risk of experiencing this negative side effect.

Hypoglycemic events felt life threatening to participants and resulted in preventable emergency room visits. Previous research on hypoglycemia in older adults has shown high levels of fear related to hypoglycemia, low psychological well-being, and high levels of diabetes-related distress (Nicolucci et al., 2015). This same research has shown that while older adults are more at risk for hypoglycemia, they are frequently unaware of hypoglycemia prevention and optimal treatment (Nicolucci et al., 2015). The greater risk of hypoglycemia resulting from sulfonylureas and insulin (Whalen & Mansour, 2009) is an important consideration in providing care in this population; this risk should be highlighted when providing diabetes education.

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Older adults with type 2 diabetes and poorly controlled diabetes-related symptoms, including physical pain, may be more prone to experience diabetes-related distress (Hu, Amoako, Gruber, & Rossen, 2007). The increased pill burden associated with the treatment of pain may also increase regimen distress—an aspect of diabetes-related distress measured in the DDS (Behavioral Diabetes Institute, n.d.; Fisher et al., 2008; Polonsky et al., 2005). As people with type 2 diabetes grow older, their experiences of pain may become more complex because of accumulated comorbidities and injuries that increased the type, frequency, and severity of the pain (Berry et al., 2015; Ehrmann, Kulzer, Haak, & Hermaanns, 2015; Gabbay et al., 2013; Gebel, 2013; Hu et al., 2007; Kirkman et al., 2012; Park et al., 2015).

Many of the participants in this study were fearful of falling and thus became more sedentary. The loss of balance may have been due to neuropathy; in older adults with diabetes, peripheral neuropathies are especially troublesome because of the harmful effects on stability, sensorimotor function, gait, and activities of daily living (Menz, Lord, St. George, & Fitzpatrick, 2004). Previous research has shown that older adults with type 2 diabetes are at greater risk for falls, and the fear of falling results in slower ambulation and reduced stride lengths (Kelly et al., 2013). Older people with diabetic peripheral neuropathy have a greater degree of risk for falling when walking on irregular surfaces—even if they adopt a more conservative gait pattern (Menz et al., 2004).

Symptoms that co-occurred most frequently were hypoglycemia and pain, with six of 11 participants reporting both symptoms. The symptom of fatigue most often occurred with balance and falling; nine of 12 participants who reported fatigue, reported poor balance. Simultaneously addressing these symptoms would likely decrease the severity and prevalence of diabetes-related distress along with improving diabetes outcomes.

Implications for Care

The long-term aim of this study was to identify clinical treatment approaches that might more successfully address the difficulties experienced by older adults in their diabetes selfcare. Intentional treatment of the particular vulnerabilities of older adults with diabetes has the potential to markedly improve their QoL.

Maintaining physical activity is an important aspect of blood sugar control and exercise is one of the four-cornerstones of diabetes management (ADA, 2015). Sedentary behaviors may lead to the loss of muscle mass, which can result in increased insulin resistance, blood sugar elevations, and an increased risk for falls and balance issues (Kalyani, Corriere, & Ferrucci, 2014). Nurses can be an integral part of preventing sedentary behaviors with older adults by identifying patients who are at risk for falls and coordinating interdisciplinary care with a focus on muscle strengthening and fall prevention. Decreasing sedentary behaviors and the risk for falls would likely decrease the risk for hyperglycemia and diabetes-related distress.

The causes of fatigue in older adults can be multifactorial. Nurses and other healthcare providers who assess for hyperglycemia, sleep habits and sleep hygiene, inactivity and polypharmacy, are in integral positions to learn key factors in the treatment and prevention

of fatigue. Fatigue, in this study, was an important component of diabetes-related distress and decreasing fatigue in older adults may well improve their overall mobility and QoL while also decreasing their diabetes-related distress.

In older adults, pain interfered with sleep, restricted ambulation, and diminished enjoyment of life. Nurses and other healthcare providers who evaluate the cause of pain in older adults can prevent diabetes-related distress by developing an effective treatment plan—especially for neuropathic pain (Hu et al., 2007).

Narratives revealed that some healthcare providers missed opportunities to address distressing diarrhea symptoms. Nurses and other healthcare providers who provide care to older adults would benefit from knowing that diarrhea is a frequent symptom of older adults with type 2 diabetes. Evaluating the medication regimen of older adults with type 2 diabetes —particularly regarding metformin—would likely improve diarrhea and blood sugar control. A direct inquiry regarding gastrointestinal symptoms with older adults is warranted when initiating treatment and adjusting dosage. If symptoms are present, time-release metformin should be considered.

In this sample of older adult participants, hypoglycemic symptoms influenced the presence of diabetes-related distress. Nurses and other clinicians of older adults with type 2 diabetes have myriad opportunities to teach about hypoglycemia avoidance and treatment. Topics for emphasis include the timing of sulfonylurea medications and/or insulin in relationship to meals—importance of not skipping or delaying meals—and the importance of keeping glucose tablets handy. Patients also need practical instruction about the best way to treat hypoglycemia.

Limitations and Implications for Future Research

The list of symptoms experienced by participants in this study may not be complete and is limited to the participant's perspective of the situation. However, respondents' comments bring novel understanding of challenges faced by this population. Findings from this study regarding healthcare provider responses may not be applicable to all older individuals with diabetes as health treatment approaches and expertise regarding aging vary. The sample size is small yet adequate by standards of phenomenological research (Creswell, 2013). Regarding access to care, all participants were eligible for Medicare because of their age and veterans were additionally eligible for Veterans Affairs delivered care, but we did not explicitly assess insurance coverage or income. This was a primarily White sample. Because cultural background can influence both the experience and expression of symptoms, greater sample diversity may yield results that are more varied. These data reflect only participants' perspectives of the situation. Future studies should include the perspective of healthcare providers and the partners or caregivers of older adults with type 2 diabetes. In addition, future studies should include systematic assessment of all medications that might influence symptoms and their relief. Studies are needed on the use of metformin with older adults, including tracking dosages and their side effects. Future studies to improve safe mobility for older adults with type 2 diabetes may advance their QoL, decrease distress, and improve diabetes-related outcomes.

Conclusion

Type 2 diabetes is an epidemic that will continue to increase with increases in the population of older adults. Expanding knowledge about the symptom experience of older adults with type 2 diabetes and diabetes-related distress may assist healthcare providers to refine their care, and subsequently improve outcomes for older adults who suffer from this disorder.

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Table 1

Interview Guide

Can you tell me about a time recently when your diabetes interfered in your ability to take care of things that are important to you? Please tell me a story about what happened. How did that make you feel? What might you like to happen in that situation? Looking back at that situation, is there something you might have done differently? Did you learn something new because of the situation? Please tell me recently when your diabetes altered your capacity to interact with family and friends. Please tell me a story about what happened. Repeat probes. Please tell me about a time recently when you had difficulty managing your diabetes in partnership with your doctor. Please tell me a story about what happened. Repeat probes. Could you describe any feelings in your body that may be due to your diabetes? Pain in feet Thirst Frequent urination Numbness Excessive sweating Blurry vision		Broad opening question: You have had diabetes for some time now - could you please tell me what it has been like for you?						
Please tell me a story about what happened. How did that make you feel? What might you like to happen in that situation? Looking back at that situation, is there something you might have done differently? Did you learn something new because of the situation? Please tell me recently when your diabetes altered your capacity to interact with family and friends. Please tell me a story about what happened. Repeat probes. Please tell me a story about what happened. Repeat probes. Could you describe any feelings in your body that may be due to your diabetes? Pain in feet Thirst Frequent urination Numbness Excessive sweating Blurry vision		Can you tell me about a time recently when your diabetes interfered in your ability to take care of things that are important to you?						
How did that make you feel? What might you like to happen in that situation? Looking back at that situation, is there something you might have done differently? Did you learn something new because of the situation? Please tell me recently when your diabetes altered your capacity to interact with family and friends. Please tell me a story about what happened. Repeat probes. Please tell me about a time recently when you had difficulty managing your diabetes in partnership with your doctor. Please tell me a story about what happened. Repeat probes. Could you describe any feelings in your body that may be due to your diabetes? Pain in feet Thirst Frequent urination Numbness Excessive sweating Blurry vision		Please tell me a story about what happened.						
What might you like to happen in that situation? Looking back at that situation, is there something you might have done differently? Did you learn something new because of the situation? Please tell me recently when your diabetes altered your capacity to interact with family and friends. Please tell me a story about what happened. Repeat probes. Please tell me a story about what happened. Repeat probes. Could you describe any feelings in your body that may be due to your diabetes? Pain in feet Thirst Frequent urination Numbness Excessive sweating Blurry vision		How did that make you feel?						
Looking back at that situation, is there something you might have done differently? Did you learn something new because of the situation? Please tell me recently when your diabetes altered your capacity to interact with family and friends. Please tell me a story about what happened. Repeat probes. Please tell me about a time recently when you had difficulty managing your diabetes in partnership with your doctor. Please tell me a story about what happened. Repeat probes. Could you describe any feelings in your body that may be due to your diabetes? Pain in feet Thirst Frequent urination Numbness Excessive sweating Blurry vision		What might you like to happen in that situation?						
Did you learn something new because of the situation? Please tell me recently when your diabetes altered your capacity to interact with family and friends. Please tell me a story about what happened. Please tell me about a time recently when you had difficulty managing your diabetes in partnership with your doctor. Please tell me a story about what happened. Repeat probes. Could you describe any feelings in your body that may be due to your diabetes? Pain in feet Thirst Frequent urination Numbness Excessive sweating Blurry vision Loose stools Shakings Difficulty thinking Light beadedness		Looking back at that situation, is there something you might have done differently?						
Please tell me recently when your diabetes altered your capacity to interact with family and friends. Please tell me a story about what happened. Repeat probes. Please tell me a story about what happened. Repeat probes. Could you describe any feelings in your body that may be due to your diabetes? Pain in feet Thirst Frequent urination Numbness Excessive sweating Blurry vision Loose stools Shakings		Did you learn something new because of the situation?						
Repeat probes. Please tell me about a time recently when you had difficulty managing your diabetes in partnership with your doctor. Please tell me a story about what happened. Repeat probes. Could you describe any feelings in your body that may be due to your diabetes? Pain in feet Thirst Frequent urination Numbness Excessive sweating Blurry vision Loose stools Shakings Difficulty thinking Light headedness		Please tell me recently when your diabetes altered your capacity to interact with family and friends. Please tell me a story about what happened.						
Please tell me about a time recently when you had difficulty managing your diabetes in partnership with your doctor. Please tell me a story about what happened. Repeat probes. Could you describe any feelings in your body that may be due to your diabetes? Pain in feet Thirst Frequent urination Numbness Excessive sweating Blurry vision Loose stools Shakings Difficulty thinking Light headedness		Repeat probes.						
Please tell me a story about what happened. Repeat probes. Could you describe any feelings in your body that may be due to your diabetes? Pain in feet Thirst Frequent urination Numbness Excessive sweating Blurry vision		Please tell me about a time recently when you had difficulty managing your diabetes in partnership with your doctor.						
Repeat probes. Could you describe any feelings in your body that may be due to your diabetes? Pain in feet Thirst Frequent urination Numbness Excessive sweating Blurry vision		Please tell me a story about what happened.						
Could you describe any feelings in your body that may be due to your diabetes? Pain in feet Thirst Frequent urination Numbness Excessive sweating Blurry vision		Repeat probes.						
Pain in feet Thirst Frequent urination Numbness Excessive sweating Blurry vision		Could you describe any feelings in your body that may be due to your diabetes?						
Loose stools Shakiness Difficulty thinking Light headedness		Pain in feet Thirst Frequent urination Numbness Excessive sweating Blurry vision						
Loose stools Shakiness Differing Eligin-headedness		Loose stools Shakiness Difficulty thinking Light-headedness						
PHQ-9 will be administered after check-list								
Is there anything that you would like to add before we conclude the interview?								

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Table 2.

Demographic and clinical characteristics of study participants, N = 16

	Mean	SD	CI 95%	Mean	SD	CI 95%	<i>t</i> -test: <i>p</i> -value
Age	68.9	3.09	66.6–71.2	81.5	3.5	79.2-83.8	<.001
Pill Burden	12	6.3	7.33–16.7	12	6.1	8.01-16	1.00
Years Since Diagnosis	11	16.1	0.9–22.9	17	18	5.2-28.8	.501
Diabetes Distress Score	3.8	0.9	3.73-3.87	3.5	0.6	3.11-3.89	.320
PHQ-9	9.5	2.1	7.94–11.2	4.8	1.2	4.02-5.58	<.001
	Frequency	Percent	CI 95%	Frequency	Percent	CI 95%	Chi Square <i>p</i> -value
Marital Status:							.401
Married	3	42.9	42.5-43.3	3	33.3	33–33.6	
Divorced	4	57.1	56.7-57.5	3	33.3	33–33.6	
Widowed	0	0		2	22.2	21.9-22.5	
Single	0	0		1	11.1	10.9–11.3	
Insulin	3	42.9	42.5–45.3	0	0		.063
Complications:							
Cardiovascular	2	28.6	28.2–29	1	11.1	10.9–11.3	.550
Nephropathy	1	14.3	14-14.6	1	11.1	10.9–11.3	1.000
Neuropathy	5	71.4	71–71.8	2	22.2	21.9-22.5	.126

Note: Men n = 7, 2 Pacific Islander, 5 White; Women n = 9, 1 Vietnamese, 8 White

Table 3

Patient Health Questionnaire (PHQ-9)

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Over the last two weeks, how often have you been bothered by any of the following problems?	
Little interest or pleasure in doing things?	Not at all Several days More than half the days Nearly every day
Feeling down, depressed, or hopeless?	Not at all Several days More than half the days Nearly every day
Trouble falling or staying asleep, or sleeping too much?	Not at all Several days More than half the days Nearly every day
Feeling tired or having little energy?	Not at all Several days More than half the days Nearly every day
Poor appetite or overcating?	Not at all Several days More than half the days Nearly every day
Feeling bad about yourself - or that you are a failure or have let yourself or your family down?	Not at all Several days More than half the days Nearly every day
Trouble concentrating on things, such as reading the newspaper or watching television?	Not at all Several days More than half the days Nearly every day
Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?	Not at all Several days More than half the days Nearly every day
Thoughts that you would be better off dead, or of hurting yourself in some way?	Not at all Several days More than half the days Nearly every day
Total = /27	
Depression Severity: 0-4 none, 5-9 mild, 10-14 moderate, 15-19 moderately severe, 20-27 severe.	

Table 4.

Demographic Sheet

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Please circle the correct answer: Female Male Age: ____ Year of diabetes diagnosis: _ Marital Status (please circle one of the options) Never Married Married Divorced Widowed Who do you live with (please circle one-if choosing other, please indicate)? Alone Family Partner Board and Care Other_ Do you have complications related to diabetes? Yes No If you have complications related to diabetes, please indicate what type by circling all the correct answers that apply: Kidney Eye Frequent Infections Nerve Heart Other (please indicate) How many pills do you take a day? _____ Do you require insulin? Yes No If you require insulin, how many injections a day do you do? _____ Did your mother or father have diabetes? Yes No