Older Adults’ Perceived Challenges With Health Care Providers Treating Their Type 2 Diabetes and Comorbid Conditions

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Type 2 diabetes is one of the most significant and growing chronic health problems in the United States. It is marked by the body’s inability to make insulin, as well as the body’s inability to effectively use the insulin it produces. Diagnosis of type 2 diabetes has increased sharply in recent decades and is expected to increase even more dramatically, with the largest increase in adults ≥ 75 years of age.

Diabetes is the seventh leading cause of death in the United States, despite often being underreported on death certificates. Furthermore, diabetes-related costs to society represent 23% of current health care expenditures, with more than half attributable to adults ≥ 65 years of age. Although prevention of type 2 diabetes is the ultimate goal, more effective management for individuals already diagnosed is crucial to mitigating the risk of complications and reducing the economic burden of the disease.

More than one in four U.S. adults ≥ 65 years of age have diabetes, with the vast majority having type 2 diabetes. Diabetes treatment for older adults necessitates special attention to the clinical (e.g., comorbidities and complications) and functional (e.g., impairments and disabilities) characteristics of this population. Most adults with type 2 diabetes have at least one comorbid condition, and as many as 40% have three or more distinct conditions. Older adults with diabetes also are at greater risk for geriatric syndromes, including depression, cognitive impairment, injurious falls, neuropathic pain, and urinary incontinence.

Comorbidities and complications can have a negative impact on diabetes self-care, health status, and quality of life. Furthermore, comorbidities and complications that do not directly affect self-care may pose competing demands, requiring substantial time, effort, and money to manage effectively.

As part of a larger qualitative study exploring how older adults manage and cope with type 2 diabetes self-care and other chronic conditions, we present here an emergent theme of older adults’ perceived challenges with the providers treating their multiple health conditions.

Study Methods

Research design
We conducted eight 60-minute focus groups with 32 older adults diagnosed with type 2 diabetes and at least one other chronic health condition; each focus group included two to six participants. Focus groups are a qualitative technique in which data are collected through semi-structured group interviews. We used focus groups to gain insight into older adults’ experiences about the care they receive for type 2 diabetes and comorbid conditions.

Sample selection
We employed purposive sampling to recruit community-dwelling adults who were English-speaking, mentally alert, ≥ 60 years of age, diagnosed with type 2 diabetes by a doctor at least 1 year ago, and diagnosed with one or more chronic conditions in addition to diabetes. Participants were excluded if they were diagnosed with Alzheimer’s disease, other dementia, stroke, or cancer in the past year, severe psychopathology (schizophrenia or bipolar disorder), or alcohol or drug abuse or if they had impaired activities of daily living (e.g., if they answered “yes” to the question...
“Do you have any difficulties with bathing, dressing, personal hygiene, or walking?”). Participants with impaired activities of daily living were excluded because the aim of this study was to explore the impact of multiple chronic health conditions on type 2 diabetes self-management; if participants were receiving assistance with activities of daily living, they also may have been receiving assistance with diabetes self-care behaviors such as medication taking and meal planning and preparation.

Participants were recruited via the university diabetes database and direct mailings and flyers in the community. We contacted potential participants via telephone to screen them for eligibility and collect data on their sociodemographic characteristics. The university institutional review board approved the study. All participants provided written informed consent before participation and received compensation for their time.

Data collection
We devised a structured discussion guide and field-tested it for flow and clarity of the questions with a group of four participants. Once the discussion guide was finalized, we began data collection.

Focus groups were conducted at community sites (recreational centers and churches), university conference rooms, and occasionally at geriatric outpatient clinics. A trained moderator asked participants broad, open-ended questions about their perceived challenges of managing type 2 diabetes amid multiple chronic conditions, how they coped with potentially interacting conditions, and whether they perceived some conditions as more severe or important than others. Co-moderators observed focus groups and wrote field notes to capture key points (i.e., written accounts of what happened during focus groups) and observations (e.g., participant affect and behaviors) about the discussions. At the end of each focus group, moderators and co-moderators met to share impressions and observations. Focus group discussions were audio-recorded and transcribed verbatim; names and identifiers were removed to protect confidentiality.

Data analysis
Data analysis in qualitative research is an iterative process in which data collection and data analysis occur concurrently. For this study, the multidisciplinary research team, consisting of two gerontologists, a health behaviorist, and a graduate student, analyzed data using standard qualitative techniques. Specifically, the researchers performed content analysis by independently marking and categorizing key words, phrases, and texts to identify codes to describe the overarching themes. Transcripts were coded and then reviewed to resolve discrepancies. This process continued until saturation was reached, that is, until no new codes emerged. After all transcripts were coded and reviewed, one member of the research team entered the coded transcripts in NVivo 8 software (QSR International, Victoria, Australia) to organize the data to support thematic analysis.

To support credibility (validity), we triangulated data sources and investigators. We converged multiple data sources, including focus group discussions, participant observation (e.g., participant affect and behaviors), and field notes (i.e., written accounts of what happened during focus groups) to verify the consistency of our findings. Furthermore, two experienced researchers outside the research team and four participants reviewed the findings to achieve researcher and participant corroboration.

To support dependability (reliability) of the data, we tracked the decision-making process using an audit trail. The audit trail is a detailed description of the research steps conducted from the development of the project to the presentation of findings.

Study Results
Thirty-two older adults with type 2 diabetes participated in one of eight focus groups (71.3 ± 7.6 years of age, A1C 6.9 ± 0.8%, diabetes duration 13.3 ± 10.7 years, BMI 32.5 ± 6.7 kg/m², 44% male, 100% non-Hispanic white, 52% college education or greater, 60% married, 84% retired [Table 1]). The six most commonly reported chronic conditions other than diabetes were hypertension (n = 23), arthritis (n = 19), retinopathy (n = 15), hypercholesterolemia (n = 12), coronary artery disease (n = 8), and neuropathy (n = 8).

Previously published findings from this focus group study of 32 older adults with type 2 diabetes and other chronic conditions identified three themes: 1) diabetes complications as a motivator, 2) prioritizing health conditions, and 3) emotional impact of comorbidity management. The majority of older adults perceived some of their comorbid conditions as being more serious than their diabetes and selectively attended to diabetes self-care based on perceived severity or importance. These older adults also reported distress and uncertainty when integrating multiple self-care behaviors for interacting conditions. Furthermore, they described feeling frustrated and overwhelmed with the multiple lifestyle, self-care, and medical demands required to manage their diabetes and other chronic comorbidities. Despite these difficulties, they acknowledged that the
threat or onset of diabetes-specific complications motivated them to improve their diabetes self-care.

Importantly, an unexpected yet prominent theme emerged specific to older adults’ experiences with the health care providers (HCPs) treating their diabetes and chronic comorbid conditions. We discuss this emergent theme and provide relevant quotations below (transcript identifiers accompany each quotation indicating each source’s identification number, sex (M/F), focus group (FG) number, age, and number of health conditions).

**Theme: older adults’ perceived challenges with HCPs**

Older participants felt that their diabetes providers (31 of 32 specifically referred to their physicians) did not understand or appreciate the difficulties of living with type 2 diabetes and other chronic health conditions. For example, many (18 of 32 participants) perceived a general unwillingness from their providers to treat their diabetes and comorbid conditions:

“I don’t know if it’s because of my other problems, but to me as soon as the doctors find that you have diabetes, they don’t want to take care of you. If I have a cut on my finger, they don’t want to take care of it because I’m diabetic. It seems like as soon as they find out you’re diabetic, whatever your problem is, they don’t want to take care of it because I’m diabetic. That’s the way I feel about it. They told me that there was surgery for spinal stenosis, but they won’t do the surgery because I’m diabetic. It makes me feel terrible. It feels like I’m never going to have anything done for me because I am diabetic. None of the doctors will want to take care of my problems. I think they’re worried about complications and malpractice. But they aren’t looking out for my best interests.” [#7F, FG 3, age 68, 4 health conditions]

Others (23 of 32) described experiences of limited support and empathy from their providers. Specifically, they felt that their type 2 diabetes providers were insensitive to their older age and remaining years of life:

“In the beginning of October, I was told that I had had two heart attacks. Every time the doctor came to see me, he kept telling me that I was going to die. He said, ‘Now you had two heart attacks and pretty soon, you’re just in a waiting position, you’ll be getting another heart attack, and that’s going to take you.’ That was horrible thing to hear! I finally waited until I couldn’t take it anymore. I said to him, ‘You know, I think God isn’t ready for me yet in heaven. He thinks there’s something that I can still accomplish during my lifetime. And until God decides he wants me, nobody else is going to take me down!’” [#32F, FG 8, age 84, 8 health conditions]

Several participants (11 of 32) attributed this perceived lack of support and empathy to age discrimination. Two women verbalized their frustration with their providers in the following dialogue:

“Sometimes I find that when doctors are treating someone my age, they say, ‘Well you’re not forty—you’re closer to death so we won’t treat you as aggressively as we would treat someone else.’” [#6F, FG 2, age 87, 4 health conditions]

“Yeah, it’s very upsetting. They’re always telling me that I’m doing great, and yet I know how I’m feeling. I’ll be 82 in July; I think I ought to know my own body by then. [laughing] And I know that I don’t feel as good as they say I do. I think doctors discriminate against older people in that respect. They say that you’re okay, and you’re not.” [#5F, FG 2, age 81, 8 health conditions]
Furthermore, many participants felt that their providers did not address their individual preferences for care. These participants wanted their providers to take the time to listen to their difficulties with multiple health conditions, as well as their preferences for specific treatments:

“Sometimes you have to talk to your doctor, especially if you have multiple health concerns. . . . I wish they would give you more time to say what you want to say to them. To me, it’s just not the same anymore. I only go because of my medicine; otherwise I wouldn’t go to the doctor.” [#12F, FG 4, age 83, 4 health conditions]

“I want the doctor to listen more. I remember when I got the diabetes. I was told maybe in the future you can go off the insulin and go with oral medication. I think I control mine pretty good. And whenever I go, I mention it to him. I hear the old story ‘Everything is working right. Don’t rock the boat!’ I would really like to go on an oral medication or pill rather than sticking myself all the time. You stick yourself in the arms, and after a while you have to move to your middle and then your thighs. After a while you’re just sore all over.” [#13M, FG 4, age 74, 3 health conditions]

Some participants (20 of 32) also felt that their care was not individualized to address their specific medical history. These participants wanted their diabetes providers to tailor treatment prescriptions and recommendations to meet their individual needs:

“My experience has been, you walk into an endocrinologist’s office, and everyone is treated pretty much the same. And the doctor wants to be the one with all the answers. And that may not be right for the person who is well-educated, proactive, and wants to go out there and see what they can do on their own.” [#2F, FG 1, age 66, 5 health conditions]

“I wish I could exercise. And the doctor says exercise, but I can’t exercise. I do this [demonstrates moving arms forwards and backwards] and move my arms, but to me that’s not exercise. I used to walk all the time, and now I can’t with the spinal stenosis and arthritis . . . . I don’t know what to do about it. They [physicians] just don’t want to understand that I can’t exercise. I can walk a little bit with a walker but not very far—like only a couple of steps. That’s not exercise. It’s moving, but it’s not exercising. But they don’t tell me what I can do about it.” [#7F, FG 3, age 68, 4 health conditions]

Finally, several older adults (10 of 32) expressed frustration with the care they received during hospital stays. They felt that the hospital health care team did not listen to their concerns about high blood glucose levels or provide the necessary medication adjustments to improve their blood glucose control:

“My experience in the hospital is that they are very naive about diabetest and what being in the hospital does to your blood sugar without anything else. When you’re in there and you’re taking medications, your blood sugar, mine really went very high. I told them I wanted to be regulated, but they were reluctant to give me what I thought I needed. And they didn’t. I had to make a big fuss for them to try and take it seriously. It’s happened to me a couple of times, and I’ve seen it happen to others.” [#27M, FG 7, age 83, 7 health conditions]

“I’ve been in for surgery a few times, and of course your sugar goes out of whack because of the stress of it all. It’s over 200, and they give me 2 units of insulin! What’s this 2 units? I take 20 in the morning and 20 at night. Why are you giving me 2? I take 20.” [#26F, FG 7, age 73, 5 health conditions]

“I take Lantus, which is a long-term insulin. You normally inject it once a day, and the level goes up, but there’s no peak. It stays that way around the clock for about 24 hours until you take another shot. I’m taking 20 units of Lantus. In the hospital the doctor said, ‘The sugar is doing something. We’re going to give you another shot of Lantus at 12 hours.’ He didn’t understand what Lantus does. That was absolutely clear, he didn’t know.” [#28M, FG 8, age 79, 6 health conditions]

Discussion
In this qualitative study of 32 older adults with type 2 diabetes and other chronic conditions, participants felt that their HCPs did not understand or appreciate the difficulties of living with type 2 diabetes and other chronic health conditions. Many perceived a general unwillingness from their providers to treat their diabetes along with their comorbid conditions. These adults described experiences of limited support and empathy from their providers, which some attributed to age discrimination. Furthermore, participants felt that their providers did not address their individual preferences for care. They wanted their providers to take the time listen to their difficulties with multiple health conditions, as well as their preferences for specific treatments, particularly during hospital stays.

These findings suggest a potential disconnect in the provider-patient treatment relationship with older adults with type 2 diabetes and comorbidities. Successful diabetes care requires teamwork between providers and patients. Two components of successful teamwork are provider-patient communication and shared decision-making, both of which have been shown to
improve patient satisfaction, adherence to treatment plans, and health outcomes.24–31

As adults with type 2 diabetes age, the health-related challenges they face can get more complicated and personal.32 For this reason, older adults may require more in-depth communication with their HCPs, in addition to individualized treatment plans that address their preferences for comorbidity management. Older adults and their HCPs should engage in ongoing discussions about what care is best for them and why. Furthermore, incorporating older adults’ preferences regarding type 2 diabetes and comorbidity treatments can have important effects on the cost-effectiveness of glycemic control.33 Thus, discussing perceived challenges to diabetes and comorbidity management may provide a systematic way to include older adults in the evaluation and treatment process, thereby enhancing the therapeutic alliance and lowering the economic burden of type 2 diabetes care.

In our study, the older adults felt that their HCPs did not understand or appreciate the difficulties of living with type 2 diabetes and other chronic health conditions. However, two recent qualitative studies with primary care providers found that providers acknowledged the complexities of comorbidity management and stressed the importance of a patient-centered approach to care, emphasizing individualization and shared decision-making.35,36 Importantly, these providers spoke of conflicts between balancing patients’ preferences with their own decisions for care and weighing the risks and benefits of adhering to treatment guidelines.36 Thus, HCPs and older adults may benefit from education and clinical tools that target shared decision-making and communication skills to build an interactive relationship in which both HCPs and adults are comfortable addressing the challenges of diabetes and comorbidity management.

Study limitations include homogeneity of the study sample with regard to race/ethnicity and residential status (community-dwelling), participant self-selection, and self-reported data. The all-white, highly educated sample is representative of the central Pennsylvania area in which the data were collected. For this reason, cultural and social variations regarding older adults’ experiences with the HCPs treating their diabetes and chronic comorbid conditions warrant further study.

Furthermore, this sample was in relatively good glycemic control (mean A1C 7.0 ± 0.8%, range 5.6–8.2%), which may have influenced their responses during the focus groups. For example, an older adult with a higher A1C level (e.g., 10%) may perceive different challenges with their HCPs that were not discussed in our focus groups. Thus, perspectives of older adults with a wider range of glycemic control are needed.

Additionally, we did not conduct focus groups with older adults with type 1 diabetes and other chronic comorbidities. These individuals may experience unique challenges managing multiple health conditions that are not reflected in our sample of older adults with type 2 diabetes.

Furthermore, the use of self-reported diagnoses may have introduced error. Older adults may have confused symptoms and minor ailments with more significant diseases; likewise, they may have forgotten to report important health diagnoses.

Additionally, our study did not include focus groups from the provider perspective. Future research with a larger, more heterogeneous sample should involve the collection of mixed-method data from physician-patient pairs to assess communication and shared decision-making regarding type 2 diabetes and comorbidity management.

Finally, the findings from this study are exploratory and should be considered hypotheses.

In conclusion, type 2 diabetes and comorbidity represent serious health care problems to the aging population. Understanding the differential impact of diabetes and comorbid conditions requires careful consideration when treating older adults, and more research is needed to explore physicians’ and patients’ perspectives on preferences for comorbidity management. HCPs may not always discuss preferences with their patients; however, our findings provide reason for HCPs to consider older adults’ preferences in the treatment of multiple chronic health conditions. Furthermore, considering that the Affordable Care Act encourages shared decision-making in health care, inquiring about older adults’ preferences for care has become even more important for providers to integrate into their clinical practice.37,39 Strategies that facilitate a mutual understanding of treatment preferences may help providers and older adults with type 2 diabetes manage multiple health conditions more effectively and with greater peace of mind.

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