In Brief

Individuals' values and preferences have a considerable impact on their motivation and, therefore, their willingness to follow treatment recommendations. This qualitative study aimed to describe older adults' values and preferences for type 2 diabetes care. Older adults valued an effective physician-patient treatment relationship and quality of life in their diabetes care. They preferred physicians who knew them as a person and were honest about their diabetes treatment and progression of the illness. When developing treatment plans, providers should assess the effect that treatment will likely have on older adults' health, while explicitly acknowledging their values and preferences for care as a prelude to better patient-centered care and potentially shared decision-making.

Listening to Older Adults' Values and Preferences for Type 2 Diabetes Care: A Qualitative Study

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Diabetes is one of the most significant and growing chronic health problems in the United States.¹ Roughly 27% of all adults ≥ 65 years of age have diabetes, with the vast majority having type 2 diabetes.¹ Despite the large numbers of older adults with diabetes, how to care for this group remains unclear because of the limited clinical trial data involving older adults²⁻⁴ and the heterogeneity, both clinically and functionally, of the older population.⁵⁻⁷

Diabetes care guidelines⁸⁻¹⁰ acknowledge the complexities of treating older patients and formally recommend that their care be individualized.¹¹ Yet, two crucial understudied domains in the individualization of diabetes care include older patients' values and preferences.^{12,13}

Values represent individuals' ideal diabetes care, or, in other words, what is most important to them in their diabetes care. Preferences represent individuals' choices or priorities derived from their values for care. Older adults may express a variety of values and preferences for care that strongly affect their treatment goals. For example, diabetes treatment may involve subjective tradeoffs between quality of life and disease progression,¹² and adults with similar clinical characteristics (e.g., age and diabetes duration) may differ in their willingness to accept treatment rec-

ommendations. Further, the demands of following a complex diabetes self-care regimen may be complicated by discordance with older adults' values and preferences.^{14,15}

Individuals' values have a considerable impact on motivation and, therefore, on individuals' willingness to carry out self-care behaviors.¹⁶ Thus, exploring older adults' values and preferences for diabetes care is a fundamental step toward improving the understanding of self-care barriers and the provision of quality care and is highly aligned with the recent interest in shared decision-making.¹⁷⁻¹⁹ The purpose of this qualitative study was to explore older adults' values and preferences regarding type 2 diabetes care.

Study Methods

Research design

We conducted focus groups with older adults diagnosed with type 2 diabetes to explore their values and preferences for diabetes care. Focus groups are a qualitative technique through which data are collected through a semi-structured group interview of approximately 5-12 individuals.²⁰ We used focus groups to gain insight into older adults' beliefs and attitudes about their personal values and preferences for diabetes care.

Participant selection

We employed purposive sampling strategies²⁰ to recruit community-dwelling adults who were English-speaking, mentally alert, ≥ 60 years of age, and diagnosed with type 2 diabetes by a doctor at least 1 year before the study. Participants were excluded if they reported being diagnosed with Alzheimer's disease or other dementia, severe psychopathology (e.g., schizophrenia or bipolar disorder), or alcohol or drug abuse. Participants were recruited via the university diabetes database and through 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's institutional review board approved the study. All participants provided written informed consent before participating and received compensation for their time.

Data collection

We devised a structured discussion guide (Table 1) and field-tested it for flow and clarity of the questions with a group of five participants. Once the

discussion guide was finalized, we began data collection. Focus groups were conducted at community sites (recreational centers and churches) and university conference rooms. A trained moderator asked participants broad, open-ended questions about their personal values and preferences for diabetes care. 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. All focus group discussions were audio-recorded and transcribed verbatim; participants' names and identifiers were removed to protect their 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 a gerontologist, a health psychologist, a graduate student, and

two research assistants, analyzed data using standard qualitative techniques.²¹ Specifically, we summarized the discussion after each focus group. We then performed content analysis by independently marking and categorizing key words, phrases, and texts to identify codes to describe the overarching themes.^{22,23} Transcripts were coded and then reviewed to resolve discrepancies through group consensus. 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 support credibility (validity), we triangulated data sources and investigators.²⁴ Specifically, we converged multiple data sources, including focus group discussions, participant observation, and field notes to verify the consistency of our findings.^{24,25} Two experienced researchers outside the research team and two participants reviewed the findings to achieve researcher and participant corroboration.²⁶ To support dependability (reliability) of the data, we tracked the decision-making process using an audit trail,²⁴ a detailed description of the research steps conducted from the development of the project to the presentation of findings.

Study Results

We conducted five focus groups, each consisting of three to seven older adults. Twenty-five older adults with type 2 diabetes participated in the focus groups (71.3 ± 7.6 years of age, A1C $6.9 \pm 0.8\%$, diabetes duration 13.3 ± 10.7 years, BMI 32.5 ± 6.7 kg/m², 44.0% male, 100% non-Hispanic white, 52.0% college degree or higher, 60.0% married, 84.0% retired; Table 2). Included with each of the quotations below are transcript identifiers indicating each source's identification number, sex (M/F), focus group number (FG), and age.

When asked about their values and preferences for diabetes care, some participants were unsure how to respond to the questions. Some said that their physician had never explicitly asked them about their values and preferences for diabetes care and, as a result, had not given serious thought to their values and preferences for care. A few others did not understand the difference between values

Table 1. List of Questions Asked During Each Focus Group

1. How did you find out that you have type 2 diabetes?
Follow-up question: What were your symptoms when you were first diagnosed?
2. How do you take care of your diabetes?
3. When I say "values for diabetes care," what does this mean to you?
If participants ask, definition of values for diabetes care: Values represent your ideal or best diabetes care. In other words, what is most important to you in your diabetes care. There are no right or wrong answers to your values for diabetes care.
4. What are your values for diabetes care?
Follow-up question: How do they coincide (or overlap) with other parts of your life?
5. When I say "preferences for diabetes care," what does this mean to you?
If participants ask, definition of preferences for diabetes care: Preferences represent your choices or priorities derived from your values for care. There are no right or wrong answers to preferences for your diabetes care.
6. What are your preferences for diabetes care?
Follow-up question: How do they coincide (or overlap) with other parts of your life?
7. Do you feel that your doctors or other members of your diabetes health care team (e.g., diabetes educator, dietitian, and nurse practitioner) address your values and preferences for care? If yes, please explain.
8. What would you change about your diabetes care if you could?
9. Is there anything else you would like to share about your values and preferences for diabetes care?

If participants did not understand a question, the moderator would reword the question until every participant grasped the main purpose for the question.

Table 2. Older Participants' Demographic and Health Characteristics

	Mean Value (<i>n</i> = 25)	Range
A1C (%)	6.9 ± 0.8*	5.9–8.2
Diabetes duration (years)	13.3 ± 10.7*	1–42
Age (years)	71.3 ± 7.6*	60–83
BMI (kg/m ²)	32.5 ± 6.7*	20.5–48.8
Mean number of health conditions including diabetes	4.1 ± 1.2*	2–7
Prescribed oral hypoglycemic medication(s) (%)	88.0	—
Prescribed insulin injections (%)	36.0	—
College education or greater (%)	52.0	—
Male (%)	44.0	—
White (%)	100.0	—
Married (%)	60.0	—
Retired (%)	84.0	—

A1C, BMI, prescribed oral hypoglycemic medication(s), and prescribed insulin injections are based on self-report.

*Reported as mean ± standard deviation.

and preferences for care. When participants expressed uncertainty about the meaning of values and preferences, the moderator provided definitions of values and preferences and explained the difference between the two terms (Table 1). Despite defining the terms and explaining the differences between them, a few participants used the terms interchangeably throughout the discussions. For example, a participant responding to the question, “What are your preferences for diabetes care?” might have referred to his or her specific preferences as both preferences and values in the same quotation. This finding suggests that not all older adults understand

the concepts of values and preferences for care.

Although some older adults expressed hesitation about responding to the questions, most described specific values and preferences for their current and future diabetes care. Two themes emerged: 1) importance of an effective physician-patient treatment relationship and 2) prioritizing quality of life in diabetes care. We discuss these themes and the respective values and preferences below (Table 3).

Importance of an effective physician-patient treatment relationship

Overall, participants valued a strong working relationship with their diabetes physicians. These adults stressed

the importance of choosing a physician whom they could trust with their diabetes treatment decisions:

“Isn’t this like the primary elections coming up? How many people can you listen to about the value of a particular candidate? With your diabetes advice, who can be your trusted advisor that you stick with? I can’t listen to everybody. I have to go to one person.” [#15M, FG4, age 76]

Further, older adults valued physicians who encouraged them to be involved in their own care and listened to their concerns:

“Help me understand what’s going on so I can participate

Table 3. Themes Representing Older Participants' Values and Preferences for Diabetes Care

Theme 1: Importance of an effective physician-patient treatment relationship

Values	Preferences
<ul style="list-style-type: none"> Importance of a strong working relationship with diabetes physician Importance of a physician who encourages patients to be involved in their treatment Importance of a physician who listens to patients' concerns about diabetes 	<ul style="list-style-type: none"> Seeing a diabetes specialist Attending a clean, organized physician's office Attending a convenient location for a physician's office Seeing physicians who take the time to get to know their patients Seeing an honest physician

Theme 2: Prioritizing quality of life in diabetes care

Values	Preferences
<ul style="list-style-type: none"> Prioritizing quality of life in their treatment Prioritizing comfort, peace, and enjoyment in life Prioritizing mobility and independence 	<ul style="list-style-type: none"> Ability to choose type and intensity of treatment Ability to make end-of-life decisions with their physician

in my own therapies Help me avoid some of the common pitfalls that I may be heading towards. . . . Be available for me to be able to talk to when there are things that I don't understand about what's going on I'm going to try my best to be compliant with what you think is in my best interests." [#15M, FG4, age 76]

"I choose a health care provider based on someone who will listen to me and what my concerns are. If I say I'm concerned about the number of low readings I'm having, I want them to respond to that I want somebody who understands that this is an individual circumstance rather than giving me platitudes of what generally works." [#12F, FG3, age 65]

Relatedly, older adults expressed specific preferences for achieving a strong physician-patient working relationship. For some older adults, seeing a diabetes specialist was most important to them:

"That was my preference. When my primary doctor said I had diabetes, I said, 'I need to see an endocrinologist.' He's a fine doctor [primary care physician]; I have the deepest respect for him, but that's the way I felt." [#14M, FG3, age 83]

Other older adults stated detailed preferences for the cleanliness of a physician's office and the convenience of getting to a medical practice:

"I want a clean, sanitary office. I want a practice that's going to value my time as well as the physician's. I want an office that is set up for my convenience as well as the doctor's. I want an office that has a changing curtain if I need to take my clothes off. It makes a huge difference in maintaining your dignity." [#12F, FG3, age 65]

"I like my doctor, but he's too far away. I don't want to get a new doctor, but it's not easy to get to my doctor because he's an hour and a half away. And if I need a doctor in a hurry, it doesn't work. I can't drive. If I'm not feeling well and my hus-

band isn't feeling well, there's no way I can get to the doctor." [#1F, FG1, age 68]

Older adults also expressed specific preferences for interpersonal interactions with their physicians that facilitated effective physician-patient treatment relationships. However, they did not discuss specific preferences for other members of the diabetes care team (e.g., nurse, dietitian, pharmacist, eye care specialist, behavioral health specialist, or podiatrist). Several older adults favored having a physician who knew them as a person:

"We're fortunate that we have a family doctor that's been treating us for some time, that knows us personally We feel that when we walk in to see him, he knows us. I think that's a very comforting feeling." [#8F, FG2, age 60]

Additionally, older adults considered honesty to be one of the most important preferences for an effective physician-patient relationship:

"I've had a doctor for a good number of years, and I trust him because he's demonstrated his ability, his concern, as well as his honesty. He'll say, 'You know, we could try this or we could try that. But I think this will work better.' And he gives you an opinion. And he stresses that I'm the only who's ultimately got to do or not do I want to be called on things . . . and I think sometimes you as the physician have to be blunt." [#18M, FG4, age 68]

Lastly, a few older adults noted the importance of having a physician who understood their diabetes in the context of their overall health. All of the older adults had multiple chronic health conditions. Thus, comorbidity may be an important factor in the expression of older adults' diabetes care preferences:

"It's hard to sort it out to just diabetes because I'm me, and I have more than just diabetes to be concerned about. Diabetes is the one I'm probably most aware of, but if something else goes out of whack, it doesn't matter what happens to the diabetes. So I think probably when I try to rank values and preferences, it

will really be in the context of my total health care." [#27M, FG5, age 69]

Prioritizing quality of life in diabetes care

Nearly all of the participating older adults valued quality of life in their diabetes care. Older adults stated that at this later stage in their lives, quality of life was more important than living as long as possible:

"I think your values and preferences change with age. For instance, I'm 76, and if I want French fries, I'm going to have them. Knock off a day of my life, I'm eating French fries! [Laughing] My point being, I'm willing to sacrifice a day of my longevity for my French fries, leave me alone! [Laughing] To me, quality of life is very important. If French fries make me happy, I'll give up a day. I'll check my blood sugar tomorrow." [#19M, FG4, age 76]

These older adults still desired to maintain a healthy life, but they prioritized comfort, peace, and enjoyment in their later years:

"I guess basic value for care is to stay as healthy as possible. To maintain a lifestyle that is enjoyable, livable Those are some of my values in terms of diabetes care." [#17F, FG4, age 66]

"My daughter-in-law has diabetes; she's not worried about neuropathy or what's going to happen when she's 70. She had trouble with a pregnancy. It's a more immediate problem. So her value was, 'What do I have to do to have a stable family at the age of 35?', as opposed to us, who are getting up there in age a little. We're just after comfort and a little more peace." [#16M, FG4, age 68]

Furthermore, they prioritized the importance of maintaining mobility and independence in their lives:

"Happy, healthy life. Enjoy life. Be mobile; get around. I still belong to the fire company. I'm still with the fire police. I'm a little old to climb ladders and squirt a hose, but I can still wave people on. And that's a thing that

drives me because it's something to do." [#18M, FG4, age 68]

"My [values] are to stay mobile and independent and feel half decent. If I was sitting around in pain all the time, there's no value in life when it gets to a certain point . . . I don't want to live that long." [#16M, FG4, age 68]

When discussing preferences, participants emphasized how a less invasive but maximally effective care plan was in line with maintaining their value of quality of life. For example, many participants were adamant about avoiding insulin and aggressive medical treatments:

"For instance, if my doctor tells me he's going to put me on dialysis, I say 'No. No way.' I want to be active. I want mobility. So keep me mobile. Keep me active. I don't want to take too much stuff in terms of medicine. I don't want to be insulin dependent. I'm not sure I want to use syringes. I'd rather live my life the way I want to live it. It's individualized. I think your preferences change when you get older. For instance, when I was working, I wanted to live so I could make money and take care of my family. Now I don't have to do that." [#19M, FG4, age 76]

An exchange between three older adults in Focus Group 1:

"What is the best way you can get me off insulin." [#3F, FG1, age 78]

"I was going to say, 'Don't give me a shot!'" [#4F, FG1, age 72]

"I've already said to the doctor, 'Before we think even of insulin, isn't there something else you can give me?'" [#2F, FG1, age 81]

Interestingly, several participants discussed end-of-life decision-making preferences in three of the five focus groups. For them, diabetes care preferences that would allow them to maintain the quality of life they valued extended beyond immediate treatment decisions. These individuals said that it was their choice whether to continue with their treatments, and it was their choice whether to be resuscitated:

"I want to be allowed to die. When it gets to a certain point,

I'd like to be able to take a pill and go. And I'm serious. I'm not committing suicide now. When you get to a point where things are tough and they can't do anything for you, I think they should be able to give you a pill. Before you have to get hooked. And I understand I have to give my own consent. I'm serious; that's what I'd like to see." [#4F, FG1, age 72]

"I've heard of the 'sleep of peace.' I look at that, and I've thought about that. To me, I'd rather have the sleep of peace. My knee won't hurt anymore. I won't be hooked up to a dialysis machine. I'm not going to go blind. If I can't have these things that I consider very basic, I'll reevaluate." [#19M, FG4, age 76]

Discussion

In our focus group study of 25 older adults' values and preferences for type 2 diabetes care, participants most valued an effective physician-patient treatment relationship and quality of life in their diabetes care. Older adults valued a physician who encouraged them to take an active role in their own treatment and listened to their concerns about diabetes. Preferences included seeing diabetes specialists and attending organized and conveniently located medical offices. Further, older adults preferred physicians who knew them as a person and were honest about their diabetes treatment and progression of the illness.

Nearly all of the older adults valued quality of life in their diabetes care. They desired a healthy life, but prioritized peace, comfort, and happiness in their later years; mobility and independence were two important determinants of quality of life. Preferences related to this value included using the least-invasive medications and medical devices available. In addition, several older adults discussed end-of-life care preferences. These adults felt it was their choice to refuse life-prolonging measures and to be allowed to die on their own terms.

Importantly, some of the older adults in the focus groups expressed uncertainty when asked about their values and preferences for diabetes care. Some said they had never been asked about this before, whereas others had not given much thought to the

matter. In addition, a few used the terms values and preferences interchangeably, suggesting that older adults may not understand the terminology. Although the terms values and preferences are frequently stated in the literature, clinicians may be better off simply asking older adults what is most important to them in their diabetes care. Translating practice guidelines into more patient-centered language may engage older adults in ongoing discussions about what care is best for them and why. A patient-centered approach that is respectful of and responsive to individual values and preferences can foster collaboration in the physician-patient treatment relationship^{27,28} and help older adults feel confident that their treatment matches the values and preferences they deem important.

Limitations of this study include homogeneity of the study sample with regard to race/ethnicity and education, participant self-selection, and self-reported data. The all-white, highly educated sample is representative of the central Pennsylvania area in which data were collected. Cultural and social variations regarding values and preferences for diabetes care among varied ethno-cultural groups warrant further study.

Furthermore, the perspectives of providers (e.g., physicians, nurse practitioners, diabetes educators, and dietitians) on the role of values and preferences in diabetes care are not known and need to be evaluated. Also, studies exploring older adults' values and preferences regarding other members of the diabetes health care team are needed. Finally, the findings from this study are exploratory and should be considered hypotheses. Longitudinal research with a larger, more heterogeneous sample should examine older adults' treatment values and preferences and their impact on self-care and glycemic control. Based on these findings, we developed a quantitative survey to examine associations among older adults' values and preferences for diabetes care, psychosocial factors, health outcomes, and glycemic control. Future research should also examine external influences (e.g., health care providers, significant others, culture, and religion) on older adults' values and preferences for diabetes care.

Clinical implications

This qualitative study is a first step in gaining a better understanding of older adults' values and preferences for their type 2 diabetes care. Health care providers may not always discuss values and preferences with their patients; however, our findings provide reason for providers to consider these issues.

Inquiring about older adults' values and preferences for care is all the more important considering that the Affordable Care Act encourages shared decision-making in health care. In shared decision-making, providers and patients share health-specific information.^{17–19} Providers present treatment options and describe their risks and benefits. Then patients express their values and preferences for care to ensure that their medical care is aligned with their rights, needs, and wishes.

When developing treatment prescriptions and recommendations, providers should assess the impact treatment will likely have on older adults' health while explicitly acknowledging these patients' values and preferences for care.^{12,13,29,30} Providers should also consider the clinical and functional characteristics of older adults^{5–7} when addressing values and preferences for care, given that comorbidity may be an important factor in the expression of older adults' values and preferences. Recognition of older adults' values and preferences for care is crucial to improving shared decision-making and quality care in diabetes.

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