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Self-Reported Goals of Older Patients with Type 2 Diabetes Mellitus

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Abstract

OBJECTIVES—New diabetes mellitus guidelines from the American Geriatrics Society promote the individualization of treatment goals and plans for patients aged 65 and older. Communicating with older patients about such complex medical decisions presents new challenges for providers. The self-reported healthcare goals, factors influencing these goals, and self-care practices of older patients with diabetes mellitus were explored.

DESIGN—Exploratory study involving semistructured interviews.

SETTING—Four clinics of a midwestern, urban academic medical center.

PARTICIPANTS—Patients aged 65 and older with type II diabetes mellitus (N = 28).

MEASUREMENTS—Semistructured, one-on-one interviews were conducted. Interviews were audiotaped, transcribed, and evaluated for recurring themes using a grounded theory approach.

RESULTS—The majority of patients expressed their health-care goals in a social and functional language, in contrast to the biomedical language of risk factor control and complication prevention, even when specifically asked about goals for diabetes mellitus care. Patient's predominant healthcare goals centered on maintaining their independence and their activities of daily living (71%). Medical experiences of friends and family (50%), social comparison with peers (7%), and medical professionals (43%) shaped patients' goals. Self-reported medication adherence and glucose monitoring was high, but more than one-quarter of patients failed to adhere to any dietary recommendations, and one-third failed to adhere to their exercise regimens.

CONCLUSION—As diabetes mellitus care recommendations for older patients grow more complex, providers could enhance their communication about such medical decisions by exploring patients' specific circumstances and reframing diabetes mellitus treatment goals in patients' own language. These may be crucial steps to developing successful individualized care plans

Keywords

diabetes mellitus; treatment goals; patient; provider communication

Enabling patients to manage their own chronic illnesses is well recognized as a vital component of successful chronic disease management.[1] Multiple studies of self-management interventions across an array of chronic conditions have shown that increasing patient involvement in daily

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care responsibilities can improve health behaviors, health status, and healthcare utilization.[2,3] A key element in this process is effective patient-provider communication.[1]

For providers, communicating with patients about a uniform prevention or treatment goal already represents a significant challenge. Such communication presents an even greater challenge when caring for older patients (≥65), for whom the goals of chronic disease management may differ from individual to individual. In the setting of diabetes mellitus care, it is unclear whether it is appropriate to apply general population standards of care to all older patients because few clinical trial data are directly applicable to the care of elderly, frail patients[4–6] and because the population is clinically and functionally heterogeneous.[7–9] To address these issues, the California Healthcare Foundation/American Geriatrics Society Panel on Improving Care for Elders with Diabetes has recommended that diabetes mellitus treatment goals be individualized for older patients.[10–12] In such guidelines, the goals of preventing microvascular and cardiovascular complications are distinct for frail and non-frail patients, and the importance of common geriatric syndromes related to diabetes mellitus, such as polypharmacy, depression, and cognitive impairment,[13] is greater for frail patients. An underlying assumption of these recommendations is that providers will make such care decisions in collaboration with patients, but little is known about how such complex discussions with patients occur in real practice.

Exploring the healthcare goals of patients is a logical first step in developing an approach to effectively communicating with older patients with diabetes mellitus about individualization of their care. Identifying the goals of patients enables providers to reframe benefits of treatments from patients' perspectives.[14–16] Studies of patient-provider communication in diabetes mellitus care have evaluated the effect of enhanced patient-provider communications[17,18] and the differences in perceptions and language of patients and providers regarding components of diabetes mellitus care.[19–21] Although these studies have illustrated the general value of understanding patients' perspectives, they have rarely examined patients' self-expression of healthcare goals. Other qualitative studies regarding the general healthcare goals of older patients have found that older patients define health in ways that integrate physical, mental, spiritual, and social aspects of their lives.[22,23] The present study has been designed to specifically examine how older patients define their healthcare goals, what factors shape their goals, and the extent to which their goals relate to self-care behavior.

METHODS

Design

This was an exploratory study using in-depth one-on-one semistructured interviews with patients aged 65 and older with type II diabetes mellitus. This methodology, specifically the grounded theory approach, was used because we desired to look in depth at older patients' perceptions and the language in which they articulated these thoughts.[24] The basic tenet of grounded theory is that no a priori theory is used in the analysis; rather, the data give rise to themes salient to respondents that subsequently form the basis for analysis.[24]

Participants

The sample of older patients with diabetes mellitus was drawn from the general medicine, geriatrics, and endocrinology clinics of the University of Chicago. Institutional review board approval was obtained before patient recruitment. The criteria for inclusion in the study required that patients be aged 65 and older and have type II diabetes mellitus and at least one additional cardiovascular risk factor (hypertension or hypercholesterolemia). It was required that patients have at least one additional cardiovascular risk factor to encourage discussion regarding the prioritization of preventive goals and treatments. Patients living in nursing homes

or with known cognitive deficits were excluded. Participants were identified through a weekly search of primary care, geriatrics, and endocrinology clinic rosters and through responses to posted advertisements in the medical center. Inclusion criteria were verified by self-report. A sample of 57 older patients was reached by phone call or responded to advertisements; 31 of these were interviewed. Of these, three were lost because of faulty audio recording, leaving 28 completed interviews for analysis.

Data Collection

Two researchers conducted the interviews from February through April 2002. To encourage candid responses that were not affected by patient-provider interaction, the interviewers identified themselves only as diabetes mellitus researchers and not as healthcare providers. The interviews were conducted using a conversational format.[25] The initial interviews[6] were used to extract themes that were then used to develop a working set of questions into a final interview guide. The questions of the interview guide were designed to explore patients' healthcare goals, diabetes mellitus care goals, experiences with diabetes mellitus, priorities for self-care strategies, and daily self-care tasks:

Exploration of patient's general health experience Goals for health

Health outcomes of greatest concern

Experience of being diagnosed with diabetes mellitus

Experiences of living with diabetes mellitus; its complications and treatments

Health outcomes of greatest concern related to diabetes mellitus

Beliefs regarding cause of diabetes mellitus

Self-care practices related to diabetes mellitus

Identification of self-care practice of greatest importance to patient

Experiences and challenges with managing medications

Experiences and challenges with weight control

Current dietary and exercise practices

Experiences with smoking cessation

The mean duration of interviews was 45 minutes

Data collection and analysis were conducted in an iterative process. Additional interviews were conducted well after "theme saturation" was reached. Interviews were audiotaped and professionally transcribed verbatim as the data were being collected.

Data Analysis

Three investigators (ESH, RGB, MHC) conferred every other week to develop a scheme for systematically coding all 28 interview transcripts. Coding took place in a two-step process. First, each investigator independently reviewed a set of three transcripts at a time and made a face-sheet summary of themes for each transcript. The face-sheet was organized to record patients' health goals, influences, and actual self-care practices. Because the interview was conducted as a conversation, themes could arise from any location within the transcript and in response to any question. Second, at meetings every other week, investigators compared interview notes and reconciled any differences between them. Patients' healthcare goals were ranked primary or secondary based on their salience for individual patients. Salience of goals was determined using the following two criteria: the degree to which a theme occupied the

content of patients' responses and the frequency with which it surfaced. This process was repeated until all transcripts had been reviewed.

Chart Abstraction

One investigator (ESH) reviewed medical records for information regarding comorbid illnesses, medications, and current risk factor levels. Twenty-seven medical charts were available for analysis. Details regarding current therapies, including specific categories of glucose-lowering agents, blood pressure-lowering agents, cholesterol-lowering agents, aspirin, and up to 11 additional medications were recorded. The reviewer recorded vital signs from the day of the interview or from clinic notes up to 2 years before the interview. Laboratory results were recorded from the day of the interview, within the month following the interview, or from clinical notes up to 2 years before the interview. Most clinical data were obtained during recent clinical encounters: blood pressure assessment, 29 days before interview (mean); glycosylated hemoglobin assessment, 60 days before; and cholesterol assessment, 179 days before.

RESULTS

Patient Characteristics

The average age of patients was 74, and the population consisted mostly of patients aged 65 to 74 (61%) (Table 1). The majority were African American (79%) and female (57%). As expected from the inclusion criteria, hypertension (100%) and hyperlipidemia (48%) were highly prevalent. In terms of major diabetes mellitus-related complications, one-third of patients had experienced a microvascular complication, and 44% had a history of coronary heart disease or cerebrovascular accident. The mean Charlson Comorbidity Index score was 3.9.[26] A small proportion of patients met American Diabetes Association care standards[10] for glucose control (37%), systolic blood pressure control (15%), and low-density cholesterol control (33%).

Healthcare Goals

Patients in the sample described their healthcare goals in global, functional terms rather than in biomedical terms. Moreover, they couched their goals in aspects of daily routine life rather than the specifics of diabetes mellitus care. More specifically, 71% of patients described maintaining independence in their activities of daily living as a health-care goal, and this was the most common primary health-care goal (43%) (Table 2). Patients aged 75 and older identified maintaining independence as a primary health goal (64%) more often than those younger than 75 (29%). The motivating factors for patients, whose main goal was maintaining their independence, included continuing daily self-care tasks and avoiding becoming a burden on their families.

> I'm living alone now but I keep praying every day, please, dear Lord, let me do my work, you know, let me get my house cleaned up because, oh, my house needs such a cleaning. (Interview 13)

> That is my goal, to remain independent, and of course, I do not ever want to become a burden to my sons. (Interview 18)

The next most common primary healthcare goal was to remain alive and healthy (29%). Secondary healthcare goals of patients included preventing complications of diabetes mellitus (25%), adhering to medications to avoid additional medications, and controlling weight and risk factors (18%). For example, one patient articulated her goals:

> I think that if I can get this weight down it will prevent a lot of the other illnesses. That's what I think. I think getting this weight down … I think it'll help my heart. I think it'll help my sugar. (Interview 5)

External Influences of Healthcare Goals

Many factors, of which the experience of peers and family members was a primary one (50%), influenced patients' healthcare goals. For some, observing friends or relatives suffer from the complications of diabetes mellitus was a motivation to seek intensified preventive care.

> And I have a friend right now who's in the hospital with a wound in her leg that they can't close. …It's frightening, it's absolutely frightening. So it's very important to me that I keep my blood sugars. (Interview 10)

For others, social comparison with peers and family led patients to minimize the severity of their own problems with diabetes mellitus.

> I try to be real with myself. …I look at my family, my family health, and my mother and my father lived to be about 75 years old. My sister passed away 2 months ago. She was about 76 and I had brothers, because there was sickle cell that ran in my family. …And I had a daughter who only lived to be 38. A brother who lived on to be 39. …And I think I'm pretty fortunate because I'm 71 and … I enjoy pretty good health. (Interview 3)

Medical professionals were the other major external influence on determining patients' healthcare goals (43%). Eighty-three percent of patients who mentioned medical professionals reported relying on their healthcare providers to develop a daily care plan.

> I've had quite a few sicknesses. …I think if it wasn't for the doctor and the medication …. if it wasn't for all of that, I wouldn't be here. You know, I'd probably be gone. (Interview 3)

Information from the mass media on prescription drugs and other medical matters was another mentioned influence on healthcare goals. For example, reports on side effects of medications motivated some patients to discontinue their medications.

> When I got the [prescription] it had a paper in it. I read it. And they had a place you could call and they give you all the different side effects. And I guess it just scared me too much that maybe my blood sugar went down. …It scared me. I told her I was going to stop taking anything. I don't want to take anything that's going to heal my diabetes and do something with my kidneys and my bladder. (Interview 4)

Self-Care Practices

Most patients' self-reported adherence to glucose monitoring (86%) and prescription drugs was high. All patients reported managing their own medicines. All patients except one were currently nonsmokers.

The greatest variability in patients' self-care practices was in diet and exercise; 60% reported making some efforts to limit fats, fried foods, red meat, or portion sizes, but 29% reported that they had not altered their diet in any way since the diagnosis of diabetes mellitus. For example, one patient divulged:

> Lot of people tell me that amount of pork will kill you. I been eatin' pork all my life. I ain't dead yet. It might kill some people and it'll kill others because they don't get no pork or nothin' else. So I don't worry about junk like that. I just eat whatever I'm used to eating. (Interview 9)

More than half of the patients reported performing some form of daily exercise that typically entailed moderate walking, calisthenics, or use of an exercise machine, but 36% reported not exercising at all. Despite being a collegiate athlete, one patient reported irregular physical activity:

> Well, I was walking for the last few years, but now I didn't walk at all last summer. I did not walk at all. The last summer I did, last summer I didn't do anything. (Interview 6)

DISCUSSION

New diabetes mellitus care guidelines[12] introduce the challenging concept that the goals of complication prevention need to be individualized for older patients. They suggest that providers will need to communicate with patients about the relative importance of preventing different diabetes mellitus-related complications. A crucial step in such communications will be an exploration of the healthcare goals of patients. This qualitative study helps to illustrate the language and content of healthcare goals for older patients with diabetes mellitus, identifies some of the key factors that shape these goals, and highlights how the self-care tasks of older patients relate to their stated goals.

We found that the majority of our older patients with diabetes mellitus used a functional language and terms of global health status rather than the biomedical language of complication prevention and risk factor control when describing their healthcare goals. Patients' predominant healthcare goal was to maintain independence in activities of daily living. These findings differ from prior studies on patient-provider communication in diabetes mellitus that have reported that the content of discussions of patients and providers centered on the concept of "control."[19–21] The fact that prior studies viewed diabetes mellitus solely as a condition of glucose control may explain this difference in results. In contrast, the results of the current study are consistent with qualitative research in the medical and sociological literature[22,23,27] that has broadly explored health beliefs and goals of patients and found that the content of patient communication often centers on their daily experiences and social difficulties.[28,29] The results of the current study suggest that older patients with diabetes mellitus may not distinguish between the prevention of different complications or between the importance of distinct treatments. The practical implication is that providers will face difficulties involving older patients in complex decisions regarding the individualization of multiple risk factor goals unless providers can frame discussions regarding treatment plans in patients' own language of global and functional terms.

A number of external factors in patients' lives that appeared to be associated with their self-reported goals and self-care tasks were also uncovered. Providers are clearly important to patients for establishing goals and care plans, but peers, family members, and the media may play an equally important role in shaping patients' expectations regarding aging and their comprehension of diabetes mellitus care. Older patients often have had a lifetime of observations and experiences regarding diabetes mellitus, medicine, their peers, and the life course that are powerful determinants of their healthcare goals.[30,31] Exploring these external influences with older patients may help providers to understand the roots of their patients' fears and healthcare goals.[32]

In terms of current self-care practices, it was found that most older patients focused on monitoring glucose levels and adherence to medications, with less-consistent attention devoted to diet and exercise regimens.[20] Ironically, of the various components of diabetes mellitus care, daily aerobic exercise and strength training are some of the few interventions formally studied in elderly patients and shown to improve functional status.[33] Patients' underemphasis on diet and exercise may be related to a traditional provider focus on risk factor control or medication management, practical limitations of comorbid illnesses, and the challenges of implementing diet and exercise regimens. To help patients realize the importance of adherence to such behaviors, physicians may need to recommend diet and exercise plans that are culturally sensitive and individualized to the individual patient.

The above findings should be considered in light of the study's limitations. This exploratory study was designed to examine the language, perceptions, and self-care practices of older patients with diabetes mellitus to inform future studies. The sample size was small and did not allow for the formal examination of strengths of associations between identified themes. In addition, there are limitations to the generalizability of the study results. The study population was drawn from community-dwelling individuals attending a major urban academic center, whose views may be distinct from those of patients attending community-based clinics or from patients living in nursing homes. The sample was also predominantly African American, and the perspective of other ethnic groups may be different.[34] In addition, only patients' perspectives were focused on, and the nature of these patient-provider relationships or providers' perspectives on healthcare goals for such patients are not known.

This study demonstrates that the healthcare goals of older patients with diabetes mellitus are couched in a language of global and functional health status. These findings suggest that newer clinical practice guidelines for older patients with diabetes mellitus, with their increased attention on the overall quality of life of patients, may be better aligned with the needs of older patients with diabetes mellitus than traditional guidelines, but challenges remain for promoting these recommendations in clinical practice, especially for nongeriatricians. Improving providers' awareness of how older patients define their goals is a crucial step in helping to individualize their communication to complement patients' agendas. Specifically, by invoking the experiences and language of older patients, providers could facilitate their involvement in developing and implementing individualized care plans. Future research needs to address specifically how providers can communicate with older patients about prioritizing different preventive treatments and self-care tasks.

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Table 1

Patient Characteristics (N = 28)

Characteristic	Value
Female, n (%)	16 (57)
Age, mean (range)	74 (65–88)
Age, n (%)	
65–74	17 (61)
75–84	9 (32)
≥85	2 (7)
Race, n (%)	
African American	22 (79)
Caucasian	5 (18)
Asian	1 (3.5)
Duration of diabetes mellitus, years, n (%)	
0–5	11 (39.3)
>5–10	6 (21.4)
>10	11 (39.3)
Complications, n (%) (N = 27)	
Nephropathy	8 (30)
Neuropathy	2 (7)
Retinopathy	3 (11)
Any microvascular complication	9 (33)
Peripheral vascular disease	7 (26)
Coronary artery disease	8 (30)
Cerebrovascular accident	5 (19)
Charlson Comorbidity Index score, mean ± SD (N = 27)*	3.9 ± 2.1
Clinical measures (N = 27)	
HbA_{1C}, mean ± SD, %†	7.2 ± 1.0
HbA_{1C} < 7% (%)	37
SBP, mean ± SD, mmHg	145 (18)
SBP < 130 mmHg, %	15
LDL cholesterol, mean ± SD, mg/dl	120 ± 61
LDL cholesterol < 100 mg/dl (%)	33
Total number of medicines, mean ± SD	7.6 ± 3.7
Medications (N = 27)	
Glucose-lowering medicines, mean ± SD	1.3 ± 0.7
Glucose control regimens, n (%)	
Diet and exercise	1 (3.7)
Oral medications	17 (63)
Therapy with insulin	9 (33)
Blood pressure medications, mean ± SD	2.3 ± 1.3
Lipid lowering agent, n (%)	10 (37)
Aspirin, n (%)	16 (59)

*One-year mortality rates for different Charlson Comorbidity Index Scores: 0, 12%; 1–2, 26%; 3–4, 52%; ≥5, 82%.[26]

†Reference range 3.9–6.1. University of Chicago Hospital Clinical Laboratories. HbA_{1C} = glycosylated hemoglobin; SD = standard deviation; SBP = systolic blood pressure.

Table 2

Major Themes (N = 28)

Theme	%
Primary healthcare goals	
Independence in activities of daily living	43
To be alive and healthy	29
To walk	3.5
Weight loss	14
Adherence to diet, exercise, or medication treatment plans	3.5
Avoidance of symptoms	3.5
Control of blood sugar levels	3.5
External influences of healthcare goals	
Peers' or family members' experience with health	50
Healthcare provider	43
Beliefs about aging/social comparison	7
Self-care practices	
Self-glucose monitoring	86
Adherence to prescription drugs	96
Diet	
No restrictions on diet	29
Some restriction of portion size or food selection	60
Strict adherence to portion size and food selection	11
Exercise	
None	36
Walking	39
Calisthenics	14
Exercise machines	7
Running	4