



Published in final edited form as:

Patient Educ Couns. 2008 September ; 72(3): 418–423. doi:10.1016/j.pec.2008.05.017.

Integrating Diabetes Self-Management with the Health Goals of Older Adults: A Qualitative Exploration

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Abstract

Objective—This study investigates the life and health goals of older adults with diabetes, and explores the factors that influence their diabetes self-management.

Methods—Qualitative in-depth interviews were conducted with 24 older adults with diabetes and other morbid conditions and/or their caregivers, when appropriate.

Results—Participants' provided a consistent set of responses when describing life and health goals. Participants described goals for longevity, better physical functioning, spending time with family, or maintaining independence. Diabetes discordant conditions, but not diabetes, were seen as barriers to life goals for participants with functional impairments. Functionally independent participants described additional health goals that related to diabetes self-management as diabetes was seen often a barrier to life goals. Caregivers, co-morbid conditions, denial and retirement were among the factors that influenced initiation of diabetes self-management.

Conclusion—Participants endorsed health goals and diabetes self-management practices that they believed would help them accomplish their life goals. Functional capabilities and social support were key factors in the relationship between diabetes self-management and their broader goals.

Practice Implications—When planning diabetes treatments, clinicians, patients and caregivers should discuss the relationship between diabetes self-management and health and life goals as well as the affects of functional limitations and caregiver support.

Keywords

diabetes; co-morbidity; self-management; goals

1. Introduction

Over 20 million adults in the United States have diabetes mellitus and almost half are over the age of 60 (1). Although glycemic control and reduction of cardiovascular risk factors can decrease the mortality and morbidity associated with diabetes, less than half of all patients adequately achieve these objectives (2,3). Increasing patients' self-management skills has been shown to improve diabetes outcomes such as glycemic control, diabetes knowledge, and

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improved diet regimens, and holds promise for improving lipids and blood pressure may be improved as well (4,5).

Despite its importance, self-management for diabetes can be time consuming and involve special concerns for older adults (6). Most adults with diabetes have other co-morbid chronic conditions, and 40% of those aged 65 or older have at least three (7). Some chronic conditions, such as hypertension and hypercholesterolemia, are considered a part of diabetes management (diabetes concordant conditions), while others, such as chronic obstructive pulmonary disease, involve different treatment regimens and guidelines (diabetes discordant conditions) (8). Among older adults with multiple morbidities the relative importance of treatment goals and plans for diabetes discordant and concordant conditions may play an important role in shaping preferences for diabetes self-management and in the prioritization of overall health outcomes (9,10). The time requirements, costs, functional limitations, and treatment complexity imposed by multiple illnesses can make it more difficult or impossible to achieve self-care guidelines (8,11). For example, physical impairments may make it difficult for patients to adhere to exercise regimens, decreasing cognitive function may make complex medical schedules difficult to follow, or multiple medications may have an associated cost that is prohibitive for the patient (8,11). Thus multiple morbidities often make it necessary for physicians and patients to prioritize treatment plans in order to achieve a doable balance that both reduces morbidity from disease, and maintains or enhances quality of life (12).

Clinicians cannot make determinations of how to prioritize treatment goals and structure plans of care without the input of patients (13–15), however little is known about patient preferences and goals for diabetes management in the context of their overall care and lives. The purpose of our study was to investigate the life and health goals of older adults with diabetes and examine the relationship, if any, between those goals and diabetes self-management. In addition, we examined the factors that influence decisions older adults make about their self-care practices.

2. Methods

2.1 Participants

We performed a qualitative study with patients recruited between October 2006 and June 2007 from outpatient clinics in the Houston area. Locations included a Veterans Administration (VA) primary care clinic, a VA geriatrics clinic, a geriatrics housecalls program affiliated with a county hospital, and a family medicine faculty practice. In addition to being over 55 years in age, inclusion criteria included having: a) type 2 diabetes, b) hypertension, and c) at least one other chronic co-morbidity. Caregivers were also invited to participate. Eligible participants were identified through chart review. Once identified, permission to seek informed consent was obtained from their primary care provider. The study was approved by the Institutional Review Board of Baylor College of Medicine.

2.2 Data Collection

Prior to the interview, investigators collected information about the patient's medical history, ability to perform Activities of Daily Living (ADLs), and demographic characteristics using questionnaires administered by study investigators. We designed an interview guide to elicit information about health care goals, effects of diabetes and other chronic conditions on daily life, self-management practices, and communication with health care providers. The five major areas of inquiry we pursued are described in Table 1. Each of the questions also had suggested probes to facilitate discussion if necessary. Interviews were allowed to follow a natural flow of conversation with the guide serving as topic areas to be covered rather than a rigid sequential arrangement of questions. Most interviews began with the question “What are the goals for

your health?” or “What are the goals for your life?” Health goals were initially thought of as pertaining to improving, treating, or remaining absent of illness while life goals encompassed all areas of a subjects’ life they deemed important. Two investigators with experience in qualitative interviewing (AN, AM), conducted semi-structured, open-ended interviews that lasted approximately 20 minutes and up to 42 minutes. The interviewer spent additional time with each subject prior to the recorded interview during recruitment, information gathering, or in the case of the house call patients, touring their homes. We aimed to interview primarily the patients themselves, with caregivers participating when present and the subject agreed. However, in some instances the patient was unable to participate in an interview, so we interviewed the family member who was the primary caregiver. This was thought to be reasonable as the caregiver was now responsible for setting and achieving goals for the subject. Interviews were tape recorded and professionally transcribed. We interviewed and enrolled participants in each of the four locations. All interviews in each location were read and analyzed until no new themes were obtained after three sequential interviews before ceasing enrollment in that location. After obtaining thematic saturation in a location, recruitment and interviews were initiated at a new location (16).

2.3 Data Analysis

Investigators generated an emergent code key using the first three transcripts (16,17). Each transcript was subsequently coded with the code key by two independent investigators (AM, JS) and then read by a third investigator (AN) for concordance. Discrepancies were discussed at regular meetings with all three coders present. Based on both these meetings and information obtained from subsequent interviews, the code key and interview guide were updated as necessary. The final code key was applied to all interviews. Using codes, transcripts were analyzed for themes pertaining to goals, diabetes and its care, or influences on the former; themes were defined as discrete topic areas that appeared in more than one interview. Proposed themes were discussed at meetings with all investigators in order to refine and expand the list as necessary. Recurrent themes were noted for all participants as well as between subgroups of participants according to location of care, primary caregivers, and other characteristics (17). We used Atlas.ti (version 5) to assist with data sorting and analysis.

3. Results

We conducted a total of 24 interviews with participants and/or their caregivers. Eight of the participants had someone in addition to themselves, usually a family member involved in their care, participate in the interview. One subject’s partner was her caregiver. Two interviews consisted of caregivers only (a daughter-in-law and daughter) because the older adult was unable to communicate. Of the ten patients interviewed in geriatric settings (housecalls program and VA), nine identified a primary caregiver other than themselves. Characteristics of study participants are given in Table 2. Fifteen males (62%) participated along with 16 (67%) African Americans and six (25%) Caucasians. Hypertension and osteoarthritis were the most common co-morbidities. Slightly more than half the participants described themselves as their own primary caregiver, although some noted having secondary caregivers.

3.1 Goals

A taxonomy of goals and other major themes appears in Table 3. For our subjects, health encompassed how one was feeling physically, but was not always strictly limited to statements about illness. Responses to the initial questions (“What are your life goals?” vs. “What are your health goals?”) yielded similar and related answers:

Q: And so what would you say your goals for your health right now?

A: Well like I was telling doctor, now I'm going to, I'm going to diet and I'm going to walk more...

Q: So what are your goals for your life? Are they different than your goals for your health?

A: ...Yeah, I had some goals there, some dreams and visions I've had and my health was going to hinder me from fulfilling those things... And then so now that's why I'm setting goals of eating better, exercising and doing everything I need to do to maintain it [health].

Although asking either question yielded similar responses, the content of the answers differed depending on the functional abilities or whether patients received geriatrics versus traditional primary care, as described in the sections below.

3.11 Goals of subjects in geriatric settings—Subjects participating in either the VA geriatrics clinic or the housecalls program discussed longevity, physical functioning, spending time with family, and maintaining independence, in response to questions about both their life and health goals. It was common for a participant to have more than one of these goals:

Oh, I want to be able to walk more. Uh, I guess that's really what I'm after, to be able to walk more, because it makes me feels better... And like it improves my health feeling, you know, I feel better... But that's about all I can think of that I want to, really want do other than when my wife comes home, we go out to eat or take small weekend trips and, you know, that kind of thing. That's it.

In the family medicine (i.e., non-geriatric) practice, one subject gave answers similar to the participants recruited from the geriatrics settings. This participant also reported having a primary caregiver other than herself like many of the geriatrics participants. In the quote below she discusses longevity as her primary goal and articulates how she does not relate her diabetes care as interfering with that life goal.

Q: What do you consider your goals for your life right now?

A: Keep living.

Q: Living? Okay. And what are your goals for your healthcare?

A: Fix it where it don't interfere with my living... The only thing that seems like it is interfering now is the stroke... Uh, diabetes? No, not really.

As in the quote above, participants who were functionally dependent, as evidenced by their need for a caregiver and/or participation in a geriatrics program, often saw another health condition, but not typically their diabetes as a barrier to achieving their life goals and achieving a healthy state.

3.12 Goals of family practice and VA primary care subjects—Participants at the VA primary care clinic and family medicine practice discussed goals of physical functioning, longevity, time with family, and independence as well, but they also described a relationship between diabetes self-management and these (life) goals:

I don't want to be in a wheelchair, I don't want to be hanging around. I want to be able to move around... I've retired and it's getting hard. So I'm really on the ball with my PCP to get it going, losing the weight... And getting a little more active... Because I want to do things... I want to travel. I want to shop. I like to go, we like to walk around the, the parks. I've got two grandkids I need to keep up with... And I can't do it if I'm walking with this cane and I'm overweight... And my overweight is my biggest problem with my diabetes

The longer, the better control I keep that diabetes the longer I'm going to live. So that's my main goal, because that is what I'm shooting for.

In these examples, patients articulated health goals as linked to their diabetes self-management. These goals included changing lifestyle behaviors such as diet and exercise, and regulating sugars. However, these diabetes goals were seen as a way of accomplishing larger life goals that were related to longevity, family, and physical functioning.

3.2 Enacting diabetes self-management goals

Although some participants did link their life goals to health goals related to diabetes self-management, this linkage was not sufficient for that goal to be enacted. Of the 12 subjects who described goals pertaining to diabetes self-management, only 8 reported actively trying to accomplish them. For these 8, there were characteristics in their external environment including health care providers, ancillary resources, and family that helped facilitate the enactment of self-management goals. Health care providers were cited as important facilitators especially when they were described as responsive to the participant. It was not unusual for the participants to use the term “we” when describing what had occurred or been decided during their medical visits:

So [my doctor] is very cool, you can sit and talk or anything...And I just tell her, 'You know, I can't find me no boyfriend, looking big and walking with a cane. I love to dance. I need to, I need to get with it.' I said 'I'm having these problems. My medication must be the thing that's making me hold this weight.' She looks back on it, 'Yeah, well January you were the same thing'...' But she's thinking about changing my medication for me to see how it works. I did an A1C. We're going to look at it today and if it's in within 7, then she may start backing me off of my Actos a little bit, because I take the Actos and the Lantus insulin and both makes me hold my weight.

These participants also utilized ancillary resources both within and outside of the health care system to reinforce ideas about changing lifestyle behaviors and medication adherence that were discussed during provider visits.

Q: What do you think your doctor, thinks is the most important part of your diabetes care?

A: Maintain the diet, but I think, from one of the last, well, just most recently today, was the physical activity... We talked more about that than my diet, because as I mentioned, I did go to that weight management program...

Other ancillary resources used to facilitate diabetes self-management included pharmacist, nutritionist, and group visits. Subjects also recalled reading books and two had even participated in clinical trials for weight loss.

Outside of the health care system, family and peers were important facilitators of goals. As seen in previous quotes, they served as a reason to want to achieve a specific goal. In addition, family and peers were described as supportive of healthy behaviors and changes by the individual:

Yeah, they [family] make sure I get my medicine and stuff like that. They're always talking to me bout taking care of myself... 'We want you to be around .. .' I know they love me and they want me around. And just like my daughter told me, I'd like to have you here when I get married and stuff like that. And I'd like to be there too. I know I got to do better.

3.3 Barriers to Diabetes Self-Management

In addition to the presence of one or more facilitators, an absence of barriers was also needed for subjects to accomplish their diabetes goals. These barriers included feelings of denial, the presence of discordant conditions, and retirement. Before creating goals of care for their diabetes, some patients discussed the need to accept their diagnosis:

When I was first diagnosed with diabetes in 2003 I think it was, I was in complete denial. Absolute denial. I, I argued with my doctor about those scores and that it was borderline and I, you know, so it's taken me a while to realize that I could be much more in control of what's happening with me than say if I had really, immediately accepted[that] 'this is what's going on with you, get on the stick with it.'

Once the importance of the disease was recognized, there were still circumstances that often prevented successful diabetes care, including diabetes discordant conditions, both chronic and acute. For example, one lady had undergone a hip-replacement after which her glucose values had not returned to pre-procedure levels:

Well, I'm, I'm fighting the diabetes thing like crazy. I had it well controlled with diet and exercise until this surgery. Actually it started with the pint of blood I left in the blood bank for my surgery and that knocked my blood sugar cockeyed and it stayed cockeyed through the surgery and it hasn't gotten where I like it since, but I'm still working on it.

In addition to illnesses, retirement also affected subjects' ability to care for their diabetes. Retirement served as either a barrier or facilitator to changing habits, especially diet.

So that's why I'm working hard, but I have to retire first to do it, because I was not eating proper at work. I would go all day without eating. Then your body feels like you're starving it...

Thus the ability to care for their diabetes by actively participating in diabetes self-care practices was at times impeded by changes in their life circumstances.

4. Discussion and Conclusion

4.1 Discussion

This qualitative study explored the relationship between life and health goals and self-care practices for diabetes in older adults with co-morbid chronic conditions. The participants in our study expressed their goals in terms of functional activities. The language used to describe health goals was often indistinguishable from that used to describe life goals. Participants described life and health goals for longevity, better physical functioning, spending time with family, or maintaining their independence. Diabetes discordant conditions, but not the diabetes itself, were seen as barriers to life goals among functionally impaired participants who required a caregiver and/or receipt of care in a geriatrics program. Participants who were more functionally independent described additional health goals that were related to diabetes self-management. For many of these participants diabetes was seen as a barrier to the life goals of function and longevity. Furthermore, health care providers and family caregivers were described by these participants as important for accomplishing health care goals. Other factors such as denial, diabetes discordant conditions, and retirement contributed to determining whether or not an individual was able to enact self-management behaviors related to diabetes.

The results of the current study are consistent with previous work that explored the relationship of treatment goals and diabetes self-management practices among older adults (12,18–20). Huang et al (18) found that older adults with diabetes described their treatment goals using functional terms rather than disease-oriented outcomes and the discussion of goals was not

linked with patients' descriptions of self-care practices. Extending these findings, the current study found that functional impairment and caregiver support are potentially important moderators of the relationship between health goals and diabetes self-management practices.

Patient-clinician communication, both general and diabetes-management specific, has been associated with improved performance with diabetes self-management (19,20). Building on this evidence, the current study suggests that communication between clinicians, patients, and caregivers is instrumental to linking general life goals to diabetes outcomes and important in framing and prioritizing diabetes self-management practices. Furthermore, the language of goals and goal-setting may be an appropriate method for framing patient-oriented outcomes and facilitating diabetes-related communication (12,18).

This study has some limitations. Our results cannot provide quantitative estimates for the associations and patterns that we observed. There are also limitations to the generalizability of our results because participants were sampled from only one geographic area. However the in-depth interview structure of our study allowed for more detailed exploration of preferences and expectations for diabetes treatments and their relationship with diabetes self-management and perceptions of treatment effectiveness. Minorities and those with no private insurance are over-represented in our sample although this provided for more information on those who might have the least resources for care.

4.2 Conclusions

Patients in our study enacted health care goals and self-management practices that they believed would help them accomplish their life goals. Although certain practices might have been done just because one was instructed to do them, priority was given to those that were more clearly linked to one's life goals. Furthermore, functional capabilities and social support were key factors in the ways that older adults described the relationship between self-management of diabetes and their broader goals. The findings of this qualitative study suggest that physicians should consider first discussing health and life goals with their older patients. Diabetes self-management practices that are consistent with patients' life and health goals should be emphasized and those that might hinder patients from accomplishing their goals may be ignored. Functional status and caregiver support are likely to be important moderators of diabetes treatment planning.

4.3 Practice Implications

Effective management of diabetes requires the active involvement of patients in partnership with their clinicians and caregivers (21). For older, chronically ill adults, communication between all involved parties (e.g., patients, caregivers, doctors) is critical for framing clinical outcomes, exchanging information, and making treatment decisions to improve health outcomes (6,22). The results of this study suggest that diabetes self-management may be further improved through the communication of how diabetes treatment goals are correlated with functional health and life goals. Collaborative discussion of diabetes self-management may be aided through the use of goal-setting methods that integrate goals into the planning and assessment of treatment. Clinical goal-setting involves setting goals that are specific, realistic, and time-limited (23,24). For goal-setting to be effective, patients and caregivers must feel confident in performing the necessary self-management steps and must feel that the specific self-management goal is related to one's overall life goals as well. For older adults it may be especially important for the clinician to ask about both life and health goals in order to facilitate the prioritization of health goals and participation in diabetes self-management planning.

For older adults, the burdens or effects of diabetes discordant conditions may hamper diabetes self-management (8). Although effects of depression and pain have been well described (25–

27), other special circumstances in the lives of older adults such as retirement and fixed incomes should be recognized and incorporated when making diabetes self-management recommendations. Furthermore, clinicians and patients may benefit from the explicit inclusion of family members and caregivers during discussions of health goals and diabetes self-management, when possible. This is especially true for functionally impaired patients who are reliant on caregivers for performing many diabetes self-management tasks. Considering the time constraints imposed on most patient-clinician encounters, new methods for accomplishing goals exploration and communication of diabetes self-management need to be developed and tested both within and outside of patient-clinician encounters.

I confirm all patient/personal identifiers have been removed or disguised so the patient/person (s) described are not identifiable and cannot be identified through the details of the story.

Acknowledgments

This article is the result of work supported with resources and the use of facilities at the Houston Center for Quality of Care & Utilization Studies, Michael E. DeBakey Veterans Affairs Medical Center, and the Primary Care Research Fellowship under the Health Resource and Service Administration (HRSA) sponsored institutional T32-HP-10031 grant. Anand D. Naik is supported by the National Institute of Aging (K23AG027144) and a Hartford Geriatrics Health Outcomes Scholar Award.

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Table 1

Patient interview guide

(1)	What are your goals for your health/life? (a) Tell me about your health and how it affects your life. (b) What would you most like to improve about your health/life?
(2)	Tell me how your diabetes affects your life and health.
(3)	Tell me about what you do in your daily life to manage your health concerns and problems. (a) Tell me about what you do in your daily life to manage on a daily basis? (b) What other health problems do you have to manage on a daily basis?
(4)	Tell me how you receive assistance from family, friends, and caregivers in managing your health conditions.
(5)	How do you discuss your concerns and goals for your health with your doctor?

Table 2

Patient Characteristics (N=24)

Characteristics	N (%)
Female Gender	9 (37.5)
Age in years	68.75
55–64	1 (4)
65–74	8 (33.3)
75–84	10 (41.7)
>84	5 (20.8)
African American Race	16 (66.7)
Primary Care Site	
VA geriatrics clinic	5 (20.8)
VA primary care clinic	7 (29.2)
Geriatrics housecalls program	5 (20.8)
Family medicine clinic	7 (29.2)
Chronic Illnesses (self-report)	
Hypertension	19 (79.2)
Osteoarthritis	17 (70.8)
Cancer	7 (29.2)
Myocardial infarction or Stroke	7 (29.2)
Kidney problems	6 (25)
Congestive Heart Failure	3 (12.5)
Chronic Lung disease	3 (12.5)
Parkinson's disease	2 (8.3)
Primary caregiver	
Self	13 (54.2)
Other	11 (54.8)

VA = Department of Veterans Administration Medical Center

Table 3
Major Themes Reported by Study Participants

Primary life and health goals reported by participants

Longevity
Spend time with family
Improve or maintain physical functioning
Maintain independence
Improve diabetes care
 Improve lifestyle (diet, exercise, weight)
 Control sugars
 Avoid complications
Factors influencing diabetes self-care goals
 Health care providers
 Ancillary and outside resources
 Family
 Diabetes discordant illnesses
 Retirement
