Factors Influencing Diabetes Self-Management Among Medically Underserved Patients With Type II Diabetes

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Abstract

In this study, researchers compare and contrast issues regarding diabetes self-management between persons in good versus poor glycemic control. The sample comprises low-income racially diverse adults with diabetes from four mid-western community health centers; 44 patients participated in eight focus groups divided by control status (HbA1c of > 9 [uncontrolled] or < 7 [controlled]). Themes common to both groups included the impact of dietary restrictions on social interactions, food cravings, the impact of mental health on self-management, and the importance of formal and informal (friends and family) support. Those in the uncontrolled groups described fear about being able to control their diabetes, confusion about self-management, and difficulty managing their diabetes while caring for family members. Although those in the controlled groups acknowledged difficulties, they discussed resisting cravings, making improvements with small changes, positive feelings about their ability to control their diabetes, and enjoying new foods and exercise. Interventions should include mental health support, incorporate formal and informal patient support structures, and address literacy issues. Health care providers and intervention personnel should be very concrete about how to do self-management tasks and guide patients on how to alter their diabetes regimens for social and other important life events.

Type 2 diabetes is a major health concern among underserved populations. Diabetes affects 9.3% of the U.S. population, with an estimated 21 million persons with diagnosed diabetes and 8.1 million with undiagnosed diabetes (U.S. Department of Health and Human Services & the Office of Minority Health, 2014b). Diabetes is the seventh leading cause of death, and inadequately treated diabetes can cause serious complications affecting the circulatory and nervous systems, kidneys, eyes, and feet. Compared to non-Latino Caucasian adults, the risk of diagnosed diabetes is 18% higher among Asian Americans, 66% higher among Latinos, and 77% higher among non-Latino African Americans (U.S. Department of Health and Human Services & the Office of Minority Health, 2014b). Latinos and African Americans are disproportionally burdened with complications and disability from diabetes, and are less likely to attain national targets for metabolic control (Center for Disease Control and Prevention, 2014; U.S. Department of Health and Human Services & the Office of Minority Health, 2014a).

Diabetes care is a vital issue for the 1,128 Federally-Qualified Health Centers (FQHCs; Bureau of Primary Health Care, Health Resources and Services Administration, & Department of Health and Human Services, 2011) and the approximately 9,000 community health center locations (FQHCs and non-FQHCs) that provide medical services for 22 million medically underserved patients ("National Association of Community Health Centers," n.d.). The uninsured and people of lower socioeconomic status suffer disproportionally high morbidity and disability from diabetes (Carter, Pugh, & Monterrosa, 1996). The adverse impact on

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these populations is compounded by inadequate access to primary and preventive health care services (Ayanian, Weissman, Schneider, Ginsburg, & Zaslavsky, 2000). Because FQHCs are vanguard providers of underserved patients, programs involving FQHC populations could be of interest to administrators, clinicians, and policymakers seeking to improve the care of the most vulnerable sector with diabetes (Walker, Engel, & Zybert, 2001).

Effective diabetes self-management is essential to achieve optimal glycemic control and decrease morbidity and mortality. Self-management is the process of actively engaging in self-care activities aimed at controlling the negative effects of an illness on one's own health. Self-management requires acquisition of knowledge and the skills necessary to appropriately engage in a complex set of behaviors aimed at maintaining health, such as self-monitoring and medication adjustments, in the context of daily living. The process involves problem solving, decision making, resource utilization, working with health care providers, and taking action. The ability to change and/or adapt behaviors is a key element (Gellman & Turner, 2012).

Studies show that patients who received self-management training have improved self-management of blood glucose, dietary habits, and glycemic control (Lirussi, 2010; Lorig & Holman, 2003; Lorig, Ritter, & Gonzalez, 2003; Norris, Engelgau, & Narayan, 2001). The health centers in this study did their best to educate patients about diabetes self-management with limited resources using existing staff—physicians, medical assistants, nurses, community health workers, and even pharmacists. One health center had a diabetes educator who worked individually with patients, two health centers (including the more rural site) offered group classes on diabetes but not on a regular basis, and one did not have any special diabetes education beyond that provided by the regular staff. Not all patients were able to attend even when available, and despite this training, some continued to struggle with glycemic control. Some centers were able to refer a portion of patients to dieticians, but not all could provide this service. Beyond limited access to comprehensive interventions, for underserved individuals with diabetes, self-management is often problematic (Heisler et al., 2007) because of difficulty paying for medications (Piette, Wagner, Potter, & Schillinger, 2004), competing priorities, low literacy (Rothman et al., 2004; Schillinger, Barton, Karter, Wang, & Adler, 2006; Schillinger et al., 2002), food insecurity (Lyles et al., 2013; Seligman, Davis, Schillinger, & Wolf, 2010), and distress related to having diabetes (Pandit et al., 2014). Yet, despite all these factors, some patients did well controlling their diabetes while others struggled.

In the setting of limited resources, community health centers strive to focus their efforts on interventions that will be most effective for patients and on those patients most in need. If time is limited, they should focus on topics that are most salient to patients as they aim for patient-centered care (Janes & Titchener, 2014; Janes, Titchener, Pere, Pere, &

Senior, 2013). However, not enough is known about the factors influencing diabetes self-management among underserved individuals. In addition, few studies have compared patient-perceived factors influencing self-management in those with good and poor diabetes control (Hill-Briggs, Cooper, Loman, Brancati, & Cooper, 2003; Stiffler, Cullen, & Luna, 2014) to learn what those who struggle need and what helps those who succeed do so well. Using qualitative methods, this study explores barriers and facilitators for diabetes self-management in underserved adults with type 2 diabetes in three small urban and one rural mid-western FQHC and contrasts those in good and poor glycemic control.

Method

Design

This descriptive qualitative study (Sandelowski, 2000, 2010) used a focus group format. Focus groups can effectively help in identifying, examining, and understanding personal beliefs, motivations, skills, and practices among underserved populations (Kitzinger, 1995). Qualitative descriptive studies "have as their goal a comprehensive summary of events in the everyday terms of those events" (Sandelowski, 2000); they produce findings "closer to the data as given, or data-near" than, for example, grounded theory (Sandelowski, 2010).

Setting and Study Participants

In 2007, the Iowa Primary Care Association (IAPCA) partnered with the University of Iowa Institute for Clinical and Translational Studies for research and evaluation purposes. This project was one of three that focused on improved diabetes care and outcomes. At the time of this study, each of four participating FQHCs employed a research coordinator who facilitated this study at their respective clinic. The research coordinator worked in an administrative and research capacity at the clinic.

The study was conducted in the four largest Iowa FQHCs. Iowa's 13 FQHCs provide medical, dental, and behavioral health services to 138,000 patients through 74 delivery sites; 40% of patients in these sites are of ethnic/racial minority status in a state with only a 6% minority population. These large Iowa FQHCs combined support more than 252,000 medical and dental health visits by 66,140 patients (Table 1).

Eight focus groups were conducted with urban and rural underserved patients with type 2 diabetes (two groups in each of the four FQHCs). The majority of patients were from the urban sites. The rural site (population around 27,000) was an additional location of a large FQHC that was otherwise predominantly located in an urban area. This site was included to increase the representation of the Latino population but was smaller and had less focus group participants. Of note, these were all small cities in a rural state, the largest

Table 1. Insurance Status and Race of FQHC Patients in the Four FQHCs.

Insurance	FQHC 1	FQHC 2	FQHC 3	FQHC 4	Race	FQHC 1	FQHC 2	FQHC 3	FQHC 4
Uninsured	48%	39%	35%	36%	White	57%	55%	60%	42%
Medicaid	28%	37%	31%	28%	Black	14%	24%	27%	8%
Private	14%	17%	27%	29%	Latino	25%	13%	10%	39%
Medicare	10%	7%	7%	7%	Other/unreported	4%	8%	3%	11%

Note. FQHC = Federally-Qualified Health Center.

of which had a metropolitan area population of around 380,000 people, and the other two had metro populations around 160,000. Participants who had participated in a previous Diabetes Survey Project were identified and invited to participate (165 total participated). Selection criteria included (a) a diagnosis of type 2 diabetes (HbA1C < 7 or HbA1C > 9), (b) currently receiving care at the FQHC, and (c) being uninsured or on Medicaid. Patients were recruited via telephone by an FQHC staff using a standardized protocol. Up to 15 patients were invited to participate in each group. Half the focus groups were composed of patients who were uncontrolled (HbA1C > 9) and half of those who were controlled (HbA1C < 7).

The University of Iowa Institutional Review Board approved the study protocol.

Data Collection

Key topics that were probed in the focus groups were identified from the literature, and jointly by University of Iowa researchers involved in chronic disease research and FQHC leadership. The discussion topics included the following areas: (a) knowledge of diabetes; (b) beliefs and attitudes regarding diabetes self-management; (c) perceived barriers and facilitators to engaging in self-management, establishing goals, and solving problems; and (d) perceived experiences at the FQHC. These topics are widely accepted as foundational to diabetes self-management strategies (Bodenheimer, Wagner, & Grumbach, 2002a, 2002b). General, open-ended questions related to each broad topic area were presented to commence discussion. These questions were followed by more specific probes to elicit in-depth information.

Each focus group was conducted at the FQHCs and lasted up to 90 minutes. Focus groups were led by the clinic research coordinators who each received training by an expert qualitative researcher (T.T-R.). All sessions were audio-taped and an FQHC co-moderator took notes. Six focus groups were conducted in English and two in Spanish. To better describe our participants, each participant completed a brief demographic information form. In addition, health literacy was assessed using the Single Item Literacy Screener (SILS) as health literacy affects diabetes self-management. The SILS asked one question read aloud: "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from

your doctor or pharmacy?" with possible responses ranging from "1" (never) to "5" (always; Morris, MacLean, Chew, & Littenberg, 2006).

Data Analysis

Focus group data were audio-taped, transcribed, and verified. Spanish transcripts were translated to English. Transcripts and field notes were subject to thematic analysis by two research assistants and two experienced qualitative investigators. The analysis involved several steps. First, the transcripts were read without any coding to obtain a sense of the data and the language that was used. Next, the transcripts were read, and segments of text were coded and discussed by both research assistants and one investigator until a final codebook was designed. The codebook included deductive codes derived from the interview guide and inductive codes that arose from the transcripts themselves. Then all focus groups were coded by research assistants using that codebook. Third, segments coded by each individual were compared for areas of consensus and discrepancy between coders. Consensus was reached if two coders assigned the same segment of text the same code. Discrepancies within the data analysis process were discussed at a meeting with the coders and other members of the research team to ensure agreement on use of codes. Finally, the different codes were grouped into larger clusters to identify themes. A summary of the key themes, exemplified by relevant quotes, are reported.

Results

Sociodemographic Characteristics

Forty-four patients participated (Table 2). In all, 66% of participants identified themselves as Caucasian, 21% as African American, 9% as Latino, 2% as Native American, and 2% as other. The mean age of participants was 55.3 years, and a 50% of participants were retired or disabled; 68% of participants were women. Participants had lived with diabetes from two months to 15 years. The majority of participants were high school graduates, but one quarter did not complete high school. The demographic characteristics are consistent with the patient population at Iowa FQHCs with the exception of a somewhat higher percentage of women (68% compared

Table 2. Demographic Characteristics of Patients With Diabetes.

Hemoglobin A1C	<7 N = 22	>9 N = 22	All N = 44
Age, years (mean)	56.5[a]	54.1[b]	55.3
Gender, number (%)			
Female	15 (68)	15 (68)	30 (68)
Male	7 (32)	7 (32)	14 (32)
Race/ethnicity, number (%)			
African American	5 (23)	4 (18)	9 (21)
Caucasian	13 (59)	16 (73)	29 (66)
Latino	2 (9)	2 (9)	4 (9)
Native American	1 (5)	0	1 (2)
Other	1 (5)	0	1 (2)
Education, number (%)			
Less than high school	5 (23)	6 (27)	11 (25)
High school graduate	10 (45)	11 (50)	21 (48)
College or more	6 (27)	4 (18)	10 (23)
Other	1 (5)	1 (5)	2 (5)
Employment, number (%)			
Employed (full- or part-time)	7 (32)	4 (18)	11 (25)
Unemployed	6 (27)	2 (9)	8 (18)
Retired/disabled	7 (32)	15 (68)	22 (50)
Other	2 (9)	1 (5)	3 (7)
Years with diabetes, number (%)			
Less than 6 months	2 (9)	3 (14)	5 (11)
Between 6 months and 1 year	2 (9)	1 (5)	3 (7)
Between 1 and 5 years	7 (32)	9 (41)	16 (36)
More than 5 years	11 (50)	9 (41)	20 (45)
SILS, mean	1.6[c]	2.5[d]	2

Note. SILS score, range: 1-5 (1 is better literacy). Percentages may not exactly total to 100 due to rounding error. SILS = Single Item Literacy Screener.
[a]Mean ages of the four focus groups: 52.0, 53.1, 54.8, 59.1 years.
[b]Mean ages of the four focus groups: 49.6, 54.1, 54.1, 60.6 years.
[c]Mean SILS scores of the four focus groups (1.3, 1.6, 1.7, 1.7).
[d]Mean SILS scores of the four focus groups (2.0, 2.0, 2.2, 3.3).

with an average of 59% women among all patients 20 and above at the four FQHCs). Demographics between the uncontrolled and controlled groups were similar except that the mean score on the literacy scale is higher in the uncontrolled group indicating less health literacy, and more participants in the uncontrolled group were retired or disabled.

Themes

The themes are grouped into two categories: themes regarding the day-to-day self-management tasks that patients must manage and themes regarding factors that affect patients' ability to complete self-management tasks. Within these categories, differences between the controlled and uncontrolled groups are highlighted. In addition, sub-themes are arranged by groups to which they apply in Figure 1. Quotes are labeled by site number (1-4), U or C for uncontrolled or controlled.

Self-Management Tasks

Self-management tasks include diet, exercise, medications, setting self-management goals, and translating information from providers into action.

Diet. Themes around changing diet predominated over other types of themes in both groups.

Eating differently from others. Participants in both groups spoke of the challenges of modifying dietary behaviors to control their diabetes while keeping everyone in the family content. Participants cited their frustrations at having to eat differently from others, which seemed unfair. One woman said, "You get angry [living with diabetes], I eat the salads and little portions while my husband can eat all the breads and pasta I can't have (1C)."

Many participants had difficulty changing dietary behaviors when others could eat all types of foods. Having certain foods in the home for others to eat was tempting for them. A female participant in the controlled group said, "It's very hard and there are always sweets in the house, and I ask please God let me eat only a little bit (2C)." Diabetes also interfered with spending time with their family because of dietary restrictions.

> It's just hard for the families to do right things half of the time because they want to go for ice cream and stuff like that. I don't go for the ice cream anymore so it's just kind of hard for the family because you want to do stuff with them but you can't. (Male participant—1C)

Some participants cited difficulties assisting with and participating in family gatherings because they were tempted to eat foods that strayed from their "diabetes diet," or there were few appropriate foods available.

> When the family have picnics and stuff . . . I have to have something special because my family, they put salt in everything. . . . they ain't going to make it special for me. You eat what they eat or you don't eat at all. I eat a salad or something, most of the time, but you know when they have family outings I don't eat . . . because, you know what it is. You guys got salt in there and I'm sitting there like . . . my blood pressure's sky high and man, I don't feel too good. (Female participant—4U)

Comorbid conditions and extra dietary restrictions. Both groups described the extra dietary restrictions because of co-morbid conditions. For some participants, their many medical conditions made it more difficult to effectively manage their diabetes. The most common were heart disease, kidney disease, arthritis, obesity, and musculoskeletal pain.

One uncontrolled group participant expressed frustration about taking Coumadin, because she was told to restrict the amount of green vegetables she consumed; however, when she was diagnosed with diabetes, she was told to eat a lot of
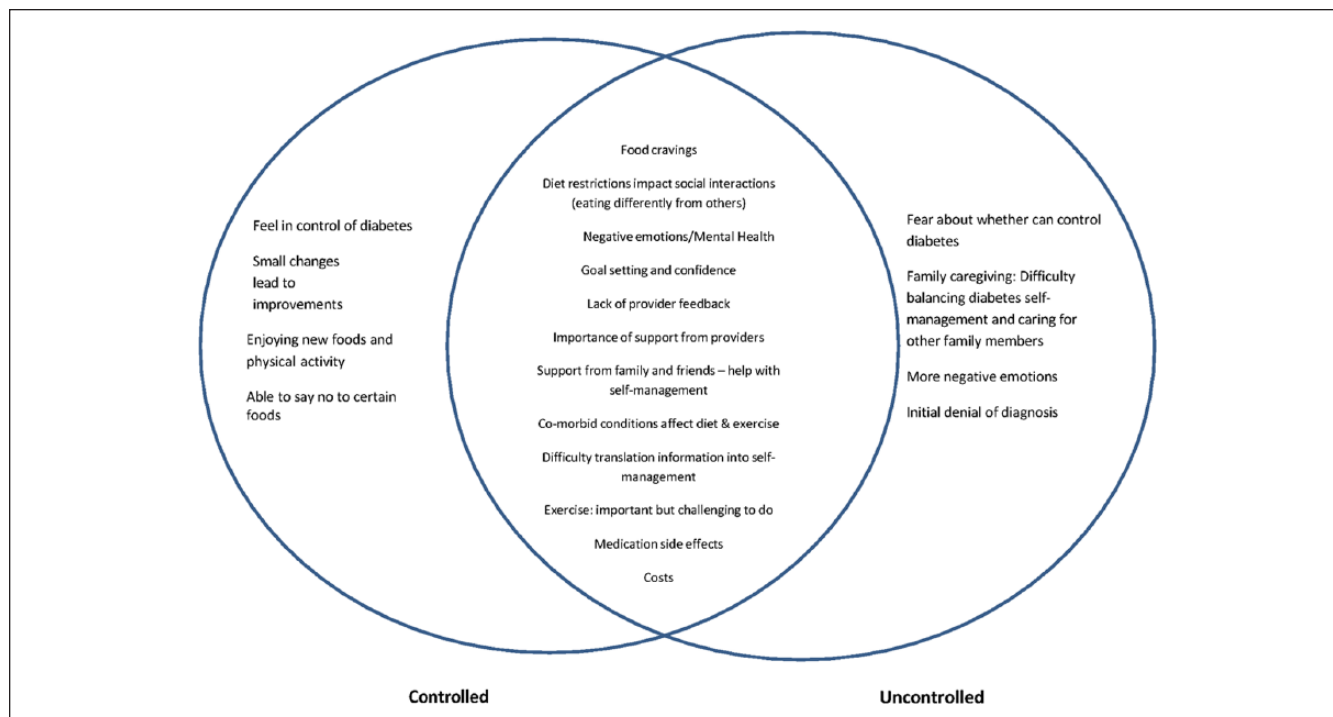
Figure 1. Themes as found in controlled, uncontrolled, and both groups.

vegetables. For others, diets were limited by advanced kidney disease (limiting protein and potassium) and by hypertension and history of a stroke (salt restrictions).

Cravings for food that should be avoided. Many patients in the controlled and uncontrolled groups discussed craving foods they should not consume and wanting to eat more of things they like. One woman said, "But oh I miss bread (1C)." A man said, "I got problems when I see something sweet, I got to, I'm craving for a Reese's cup. I want it . . . I just can't help it but I know it's wrong and it's hard sometimes for me (3U)."

Even though controlled group participants also craved foods they could not eat, they spoke differently about their daily self-management in regard to "being in control." Several reported suppressing the temptation of eating unhealthy foods to make healthier food choices such as drinking water instead of carbonated beverages. One man said, "I am a cook so it's hard, I don't get to eat what I fix everybody else. Sometimes it's tempting but I try not to (1C)." Another woman said, "Not being able to guzzle on sweets when you want to. And I really get the cravings. And I just keep saying no, no, no, no (3C)."

Exercise. Many participants in both groups stated the importance and benefits of being physically active. However, many reported they did not exercise because of co-morbid conditions, lack of motivation, or other factors. Many participants reported difficulty being physically active because

of pain, shortness of breath, musculoskeletal sprains or strains, and obesity. A female controlled group participant mentioned, "I'm trying to get out and exercise more. It's really hard because I have degenerative disk and joint disease and severe arthritis (3C)." Yet, some discussed creative ways to engage in physical activity such as walking the dog, walking around the house, or arm and leg exercises while watching television.

Medication issues. A common theme in both groups was side effects of diabetes medications (i.e., diarrhea from Metformin). A female uncontrolled group participant stated,

> My feet were swelling up and the lower half of my legs were swelling up . . . [My doctor] said well you have the choice either you take the drug and your feet swell up or you don't take the drug and your blood sugar goes up. Which would you rather have? (1U)

Another common challenge was remembering to take medications on time.

Setting self-management goals. Setting and achieving self-management goals was challenging for many participants. Some participants expressed a lack of motivation, limited capacity to self-manage, and ongoing difficulties breaking familiar habits and routines. Only a few reported they set goals with their providers (mostly in the controlled groups), but many in both groups had set goals on their own. Most

often, these goals were to lose weight or decrease their blood sugar. However, some described not having the confidence or lacking the ability to achieve their goals and the barriers that made it difficult. One female uncontrolled participant said, "You get to the point where . . . I'm trying and I'm trying and I'm trying and it's not doing any good, I mean, just forget it, you know? Because I've been there, it's just after 20 years, yeah I'm fat (4U)." A second woman said,

> I do set goals but I don't achieve them. For example . . . I say this week I'm not going to eat tortillas. I go three days without tortillas, and then the third day I eat them, and I fill myself! I try to focus but I can't. It seems hard for me not to eat tortillas. (2C)

Translating information from providers into actions. Participants in both groups discussed challenges in understanding and translating information given by their providers into diabetes self-management actions regarding eating a balanced diet, being physically active, and monitoring their blood glucose. One woman said,

> She (provider) helps me with my goals. She is upset that I don't exercise as much as I should. But she doesn't give me . . . like in there today, they told me I don't have to actually walk. I can just sit on the couch and swing my legs back and forth and flap my arms and stuff like that. They never told me these things. (4U)

Some participants cited not knowing where to begin with adhering to these instructions and would eventually give up and follow their own ideas and/or impressions. One woman said, "I don't know what I am supposed to do and what not to do . . . I don't know where you can go to find out what it is you are supposed to do (1C)."

Other participants knew that certain foods were not good for their diet, but requested assistance to avoid and/or control eating these foods. Nonetheless, some tried to follow provider dietary instructions and incorporated these into their daily routine. However, some had trouble reconciling information from different sources that differed in their approaches. One woman said,

> I went to the dietitian and she gave me the plate method . . . Ok then you go out and buy a diabetic cookbook and do you think it has the plate method in there? NO, it has an exchange thing. Well I get sick just eating a piece of meat and a starch and a veggie. I mean I would like to eat some of those diabetic casseroles but I don't know how to employ that in with my plate method so you get frustrated. So I just eat. (1U)

Factors That Affect Ability to Self-Manage Diabetes

A number of factors affect patients' ability to complete self-management tasks including understanding about the causes of diabetes and feelings at diagnosis, feelings about being able to control diabetes, mental health issues, costs, family caregiving responsibilities, and social support from family, friends, and providers.

Understanding of the causes of diabetes and feelings at diagnosis. The majority of the participants in both groups had a general understanding of the causes, symptoms, and complications of diabetes. Most participants viewed diabetes as a consequence of not eating healthy or exercising, being overweight, and because of ethnicity and/or heredity. Some Latino participants in both groups mentioned "susto" or a "traumatic event" as a potential cause of diabetes. One man said, "They said that he got it from a susto (fright). An accident happened and my father killed a man it scared him (2C)."

Many patients in both groups indicated that when they were first informed that they had diabetes, their feelings ranged from anger, fear, depression, denial, and uncertainty to acceptance. Descriptions of denial came only from three participants in the uncontrolled groups. One woman stated, "It's just devastating . . . I was actually diagnosed the first time 13 years ago. But for the longest time I acted like it wasn't there. Until 2 years ago I had a stroke (1U)."

Feelings about being able to control diabetes. Feelings about their ability to control their diabetes seemed to differ between the two groups. Participants in the controlled groups seemed more optimistic, had a positive outlook about their quality of life, and were willing to make changes in their lifestyle. One man said, "Because if you watch what you eat and do exercise, and you learn little bit and what fruit to eat, you can do well (2C)." A woman said, "[Diabetes is] a hindrance. You just have to know how to control it. Diet. Exercise (3C)."

Many in the controlled group reported that they adhered to recommendations for self-management from their provider. They were able to put these recommendations into self-management actions particularly by focusing on one small change at a time. One man said making small changes was the key to success in managing his diabetes. He said, "I made a lot of little changes from the very beginning . . . they [dietician and doctor] just said make a lot of little changes and maybe that will help. That's what did it. I did lose some weight (1C)." A woman echoed this: "Not eating so many tortillas and candy, that works [for setting goals]! It really works (2C)."

Some viewed the diagnosis of diabetes as an opportunity to take on a healthier lifestyle. Participants in the controlled groups talked about portion control and substituting one food for another. Some controlled participants also discussed enjoying some new foods and looking forward to exercise. One man said, "I like eating salads so probably everybody here wishes they were me. Nothing is really too hard for me to stick to (1C)." A second man imparted, "When one starts to exercise, it's very hard, but you just have to get used to it, and after a while your body wants it. It happens to me when I exercise and my body asks for it (2C)."

In contrast to the positive outlook of the controlled group, several participants in the uncontrolled group reported a lack of control over their diabetes. Some also described fear regarding eating and medication and its effects on their blood sugars. One woman said, "I panic and start starving myself [when overeats or forgets insulin]. I am then afraid to eat anything. And then I slowly start back (1U)." Another woman described,

> I am really trying to change my habits but it's hard . . . you pick something up you look at to see what the nutrition facts are, sugar 33 grams oh my god, you put that back. It's very hard to be on this. I am scared of it. (1U)

Mental health issues. Mental health issues (social isolation, loss, anxiety, stress, and depression) were described by controlled and uncontrolled participants (though more uncontrolled patients), and impacted ability to self-manage their diabetes. One man reported that it is ". . . just the diabetic part of it, feeling the way I feel. And sometimes I can't even leave my house. You know, I feel very withdrawn and it is hard to get out (4C)." A second woman stated,

> You know for a while I was pretty depressed because I lost my mother and I quit taking my medicine and I have high blood pressure from all the problems but I was hurting myself so I talked to my doctor about it. (1U)

Costs. Financial constraint was a common theme; these constraints impeded participants' ability to obtain adequate medications, purchase healthful foods, and attend clinic visits. One woman reported, "I am on a fixed income and I only get so many food stamps and the cookbook, you can't afford that stuff in that cookbook (1U)." While another woman said, "I don't have insurance, that's why I can't come to the clinic that often, because we don't have enough money (2U)." Controlled participants also discussed financial hardship but discussed working with their doctors to decrease medication costs or get financial assistance. One woman said,

> When the doctor writes the prescriptions, I let them know that like "Hey, I've got $28 I can pay out of my bills" . . . and if I've got to have another medication, it's got to be one that my drug coverage can cover. (4C)

Family caregiving responsibilities. Family caregiving responsibilities could also make diabetes self-management more challenging. Some participants, particularly in the uncontrolled group, had taken on the role of family caregiver and placed the needs of others first; this resulted in neglecting the management of their diabetes. One woman reported,

> My daughter is very sick. She cannot do anything for herself. I haven't done anything for myself . . . I get very hungry and I eat the same thing I give her because I do not have time to cook for myself. I know that's bad for me, but I cannot take care of myself the way I should be. (2U)

Another woman found it challenging to be physically active because she had to be at home caring for grandchildren: "Like I said I got my little grandson all the time so I really don't have much time for myself (3U)."

Family support. Social support from family members helped participants stay on track with their diabetes self-management. They valued family support during difficult times and benefitted from talking to and spending time with others. Some participants had family members with diabetes who would share what was discussed with their own providers and information about diabetes self-management (e.g., cooking recipes). Some participants found these exchanges of information useful as they provided possible ways to improve self-care and problem solve.

Participants in both groups shared that some family members (e.g., children, grandchildren) would remind them to take medications and check their blood sugars. One woman said, "My kids check on me. My oldest boy just found out he's a diabetic so we call each other and check up you know (1C)." Also, family members were instrumental in monitoring the participant's dietary intake by providing verbal reminders about foods they should not consume, being a positive influence, and encouraging the purchase of healthy foods during grocery shopping. One woman said, "It helps if you have someone eating along with you saying don't eat this or don't eat that. My sister encourages me to buy healthy food like I buy wheat noodles instead of regular noodles (1U)."

Support from friends. Participants in both groups identified the importance of having a peer or friend support/network, in particular composed of others with diabetes. Peers shared information about what worked and did not work during their daily self-management. One controlled male participant said "[I] just talk to my friends that have the diabetes and explain to them what's going on with it to see if they have situations (1C)." Some participants also exchanged information with peers seeking suggestions, ideas, or what was discussed with their friends' providers, as well as information found on the Internet.

Friends would assist with grocery shopping and reminded each other to resist purchasing foods they should eat infrequently. One woman said, "We are best friends . . . We will go shopping together and sometimes I go to get something and she will go 'you know you shouldn't have that' (1U)." They also checked on one another, particularly when participants either had no family or they were not available. The combination of family and peer support had a strong presence in both groups. Participants in three of the four uncontrolled groups and none of the controlled groups spontaneously commented that they found the focus group a helpful opportunity to talk with their peers.

Provider support. In addition to the informal support provided by family and friends, participants in both groups acknowledged the support and guidance they received from providers

to address needs, facilitate problem solving, and provide guidance during difficult times. One woman stated, "When your doctor participates in what you're doing, it makes a lot of difference (4U)." Descriptions of support from doctors focused on doctors listening to them and answering their questions. One woman in the uncontrolled group said, "I love the doctor I have now. She sits down and talks to me, asks me questions (1U)." Support was also described from other types of health care providers such as dieticians and nurses. These descriptions focused on help with motivation, specific diet advice, cookbooks, and other instrumental help. One woman stated,

> I swear by the dietitian here, she's wonderful. Every time I got off track I would have to ask the doctor, I think I need to go see the dietitian again. I need a little pep talk and that's what she'll do, she gives you a pep talk. (1C)

Another woman described help from nurses and medical assistants at the clinic,

> I've been having a really bad time with sweets . . . I was doing pretty good. All at once it's been up and down up and down. I still don't have it totally under control, but M—and they are working on helping me with it. (3U)

Spanish speakers were particularly enthusiastic about having caregivers they could communicate with directly or through interpreters; "Here everyone is so nice, and they treat me so well! And since I don't speak English, they always have an interpreter here for me. Here they listen to the questions that one has (female participant—2C)."

Although provider support could be important, some participants in both groups cited dissatisfaction with their providers during office visits and when discussing their care plan. Some stated that not enough feedback or recommendations were given during office visits and several changed providers in hopes to have better rapport and support. One woman in an uncontrolled group said, "Dr. XXX, I just don't have a lot of faith in him. I would really like to change doctors; I just don't have a lot of feedback from him at all (1U)." Another participant stated, "I had to change doctors too. Because my regular doctor is gone. I come in, he comes in, he goes out and gets my prescription and when I am ready to ask my question he is gone (1C)."

Informal support from peers and family overlapped with formal professional support in that information from providers was shared among those in informal networks. For example, one woman said, "My sister is a big help with different things she has found out from her doctor that I have tried and has worked for me (1U)." However, this could sometimes be confusing for participants if information from informal and formal networks differed. One woman was confused because friends and family were telling her things they heard about diabetes care from their doctor, but she had not heard the same advice from her doctor.

Everyone says, well my doctor said to watch this, this and that. Well my doctor never said that to me . . . So it's hard for me to understand, should I be worried about things like that too. (1U)

Rural versus urban. As described, the majority of participants are from small urban areas (around 180,000 people in each area). Comparisons with the more rural participants are limited because of the smaller number of participants from a more rural area. Additionally, participants in the rural groups were mostly Latino and Spanish-speaking. Themes in these groups were similar to the other groups with the exception of those themes specific to Latino culture (i.e., susto) or language barriers.

Discussion

This article describes the diabetes self-management experiences of low-income racially and ethnically diverse adults with diabetes treated in community health centers in the Midwest. This article highlights important themes for this group and compares themes found among those whose diabetes was well-controlled (controlled) versus those with poor control (uncontrolled).

Themes common to both groups included the impact of dietary restrictions on social interactions, food cravings, the impact of mental health on self-management, and formal and informal (friends and family) support. Those in the uncontrolled group described fear about being able to control their diabetes, confusion about self-management, and difficulty managing their diabetes while caring for family members. Although those in the controlled group acknowledged difficulties, they also discussed resisting cravings, making improvements with small changes, having positive feelings about their ability to control their diabetes, and enjoying new foods and exercise. Both groups described lack of feedback from providers, switching doctors in search of better support, and enthusiasm for providers who would listen. In both groups, participants' co-morbidities lead to difficulty exercising or added dietary restrictions. Uncontrolled group participants had lower health literacy.

In both groups, diet alterations needed for diabetes were perceived to interfere with social interactions. Some participants in this study avoided some interactions with family and friends that involved food; they felt they could not participate fully because the food was not appropriate for their diabetes. Similar problems have been described in low-income Latino and African American adults with diabetes who have non-adult children (Laroche, Davis, Forman, Palmisano, & Heisler, 2008). One meta-ethnography highlighted the importance of "strategic non-compliance" for adults with diabetes to avoid limiting social activities because of their diabetes (Campbell et al., 2003). This means that patients strategically change their diabetes regimen (diet restrictions, medications, testing, and so forth.) to allow for social events. This allows patients to achieve a better balance between

quality of life and diabetes self-management demands, and in one study, these patients had better glucose control (Campbell et al., 2003). This is different than just abandoning dietary recommendations and then feeling guilty later.

A second finding was that participants needed better guidance on how to turn recommendations from providers into concrete self-management strategies and reconcile varied information sources. This re-emphasizes the need for effective diabetes self-management support especially in these vulnerable populations (Feathers et al., 2005; Spencer et al., 2011).

Other more global factors influenced patients' self-management. Participants in both groups (especially the uncontrolled groups) described strong emotional responses (sadness, fear, anxiety, distress, and depression) both to the diagnosis and to ongoing self-management needs. These feelings affected the ability to complete self-management tasks. Difficulty with self-management tasks and poor outcomes (poor glucose control, lack of weight loss) led to further frustration and distress. However, participants in the controlled groups consistently described a more positive outlook toward their future health and ability to control their diabetes. In contrast, participants in the uncontrolled groups were more likely to describe fear, uncertainty, and lack of control regarding managing their diabetes. This difference in orientation was also seen in another study among low-income urban African Americans (Hill-Briggs et al., 2003). This study found a more positive orientation toward problem solving, more rational decision making, and a more positive interpretation of past experiences (positive and negative) among the well-controlled group compared with the poorly controlled group. Among participants in a diabetes control program in New England, those in better control (a) took diabetes more seriously, (b) knew diet control was central and "how to 'cheat' strategically," and (c) viewed lifestyle changes as a "normal part of their daily routines" (O'Connor, Crabtree, & Abourizk, 1992). Those in negative control were less positive, more fearful of hypoglycemia and insulin, struggled with acceptance of diabetes and lifestyle changes, and felt guilty about cheating. No information about race or income of the participants in that study is provided (O'Connor et al., 1992; O'Connor, Crabtree, & Yanoshik, 1997).

The current study is consistent with some of the work on diabetes self-efficacy and perceived control (which is different from locus of control). Particularly in underserved populations, these concepts are linked to quality of life and glycemic control (Aljasem, Peyrot, Wissow, & Rubin, 2001; Campbell et al., 2003; Hernandez-Tejada, Lynch, Strom, & Egede, 2012; Howorka et al., 2000; King et al., 2010; O'Hea et al., 2009; Sarkar, Fisher, & Schillinger, 2006). Although not formally measured, in the current study, the controlled group described a belief in the ability to do the tasks required (self-efficacy) and a perception "that one's life is manageable" (perceived control). This is despite the fact that both controlled and uncontrolled groups in this study struggled with cost and other barriers.

Previous studies also highlight the strong emotional distress that can be seen in diabetes (Campbell et al., 2003; Fisher et al., 2010; Fisher et al., 2007; Gask, Macdonald, & Bower, 2011; Spencer et al., 2011). There is an association between diabetes and clinical depression (Roberts et al., 2012). Depression poses a significant barrier to self-management, but treatment in this low-income population might be complicated by limited access to mental health providers. Distress related to having diabetes also can be a separate phenomenon from full clinical depression (Fisher et al., 2009; Fisher et al., 2007) but still have significant effects on diabetes outcomes (Pandit et al., 2014). Some diabetes self-management programs have shown a decrease in diabetes-related anxiety and distress, and might be models to build on in disadvantaged populations (Concha et al., 2009).

A final finding was that patients relied on a combination of formal and informal support systems to help with diabetes self-management; these included not only health care providers (formal) but also family member, friends, and others with diabetes (informal). This is consistent with other literature (Gleeson-Kreig, 2008; Gleeson-Kreig, Bernal, & Woolley, 2002; Wilkinson, Whitehead, & Ritchie, 2014). Other research reinforces the importance of social support for diabetes self-management, especially in vulnerable populations (Chlebowy, Hood, & LaJoie, 2010; Fisher et al., 2000; Ford, Tilley, & McDonald, 1998; King et al., 2010; Rosland et al., 2008; Trief, Grant, Elbert, & Weinstock, 1998). Three aspects of social support are of particular relevance in our study. One, families can be a major source of support as well as a major stressor (Carbone, Rosal, Torres, Goins, & Bermudez, 2007; Cherrington, Ayala, Sleath, & Corbie-Smith, 2006; Gask et al., 2011; Laroche et al., 2008; Laroche et al., 2009; Rosland, Heisler, & Piette, 2012). Particularly in the uncontrolled group, patients describe neglecting their own diabetes self-management to care for family members as has been seen in some other groups of people with diabetes studied. (Carthron, Johnson, Hubbart, Strickland, & Nance, 2010; Rosland, Heisler, Choi, Silveira, & Piette, 2010; Wilkinson et al., 2014). Two, both groups described some frustration with the feedback they received from their providers, and searching for providers who would listen to them and have time for questions. Those who found this support described support not just from doctors but other providers (dieticians, nurses, etc.). This reinforces the importance of good provider–patient communication and a team approach to support. Other studies have found that provider support can play an important role in diabetes self-management (Carbone et al., 2007; Chlebowy et al., 2010; Rosland et al., 2008; Thorne & Paterson, 2001). Third, participants described the interplay between formal and informal social networks. Participants, family, and friends shared diabetes information from various health care providers and other sources. Information given by one health care provider to their patient might be passed among many adults. Those who are not getting the information they need from their health

care providers might seek information through their networks of friends and family. Other studies also describe the sharing of information among peers and family (Chlebowy et al., 2010). One concern is that advice given in one specific context for a specific patient might not apply to another patient with diabetes.

Overall, many themes resonate with those found in other qualitative studies of adults with diabetes among different populations both in the United States and in other countries (Campbell et al., 2003; Stiffler et al., 2014; Wilkinson et al., 2014). As one might expect, one theme that resounds in this group more than some other studies is barriers related to cost, including health care, medications, and healthy food. This suggests that this group of underserved individuals struggles with some of the same issues as others with diabetes and needs some of the same support mechanisms/programs to succeed. Unfortunately, they have fewer resources for support, and they might need additional support beyond the traditional programs. However, within this disadvantaged population, there remain those who despite their challenges feel empowered to control their diabetes. Finding ways to empower more of these patients to control their diabetes is the challenge.

These findings have implications for providers and interventions. Providers need to address coping mechanisms for adults with diabetes regardless of whether they meet the diagnosis of clinical depression or anxiety (Fisher et al., 2007). Key to assessing support needs might be to provide an opening to discuss the emotional impact of diabetes on patients during visits (Gask et al., 2011) or perhaps screening with a distress scale (Fisher et al., 2009; Gask et al., 2011; Roberts et al., 2012). Finding ways to enhance provider–patient relationships and provide other support to patients is important especially among patients with uncontrolled diabetes (Slean, Jacobs, Lahiff, Fisher, & Fernandez, 2012; Thorne & Paterson, 2001). Patients need to feel they have control. Patients need concrete support and suggestion for diabetes self-management and a follow-up system of support where they can get their questions answered. This support could be enhanced by health care team members other than the primary care provider. Education and behavioral interventions could benefit from including family, friends, and peers. Assistance is also needed in addressing challenges caused by comorbidities. To minimize social isolation, providers need to proactively problem solve with patients around how to handle social interactions involving food (Campbell et al., 2003). Providers and other trained staff can give patients the tools to make changes to their diabetes regimen (Thorne & Paterson, 2001) for social occasions safely rather than through trial and error without provider knowledge (Campbell et al., 2003). This could include acknowledging situations in which diabetes control might not be perfect. Peer support interventions or support groups might also be beneficial (Tang et al., 2014).

The strengths of our study included a focus on underserved racially diverse populations and the inclusion of community health center staff as partners involved in design, recruitment, and data collection. These results are most applicable to low-income older adults with diabetes served in community health centers. Because transportation to the focus groups was not provided, we might have limited our sample to those who either had transportation or skills in accessing public transportation. This might explain why transportation issues were not a strong theme among this group. A strength of the study is the involvement of Spanish-speaking Latino participants. These were the only participants from the most rural site. Thus, we cannot comment on the experiences of other more rural residents. Their themes were similar to the small city urban dwellers except for those related to Latino culture and language barriers. Additionally, 68% of participants were women, and thus, some of the findings might relate better to women.

Conclusion

Low-income adults with diabetes face many challenges to diabetes self-management including strong emotional reactions and depression, difficulty translating provider advice into concrete self-management tasks, effects of diabetes on social interactions, comorbidities, and balancing family obligations and self-management. These patients rely on formal and informal support systems that overlap. Those with better control describe faith in their ability to make changes for their diabetes. Interventions need to include mental health support, incorporate formal and informal patient support structures, bolster self-efficacy, and address literacy issues. Health care providers and intervention personnel also need to be very concrete about how to do self-management tasks and guide patients on how to alter their diabetes regimens for social and other important life events.

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