Culturally tailoring patient education and communication skills training to empower African-Americans with diabetes

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ABSTRACT

New translational strategies are needed to improve diabetes outcomes among low-income African-Americans. Our goal was to develop/pilot test a patient intervention combining culturally tailored diabetes education with shared decision-making training. This was an observational cohort study. Surveys and clinical data were collected at baseline, program completion, and 3 and 6 months. There were 21 participants; the mean age was 61 years. Eighty-six percent of participants attended >70 % of classes. There were improvements in diabetes self-efficacy, self-care behaviors (i.e., following a “healthful eating plan” (mean score at baseline 3.4 vs. 5.2 at program’s end; $p=0.002$), self glucose monitoring (mean score at baseline 4.3 vs. 6.2 at program’s end; $p=0.04$), and foot care (mean score at baseline 4.1 vs. 6.0 at program’s end; $p=0.001$), hemoglobin A1c (8.24 at baseline vs. 7.33 at 3-month follow-up, $p=0.02$), and HDL cholesterol (51.2 at baseline vs. 61.8 at 6-month follow-up, $p=0.01$). Combining tailored education with shared decision-making may be a promising strategy for empowering low-income African-Americans and improving health outcomes.

KEYWORDS

Diabetes, Patient empowerment, Diabetes education, Shared decision-making, African-Americans

INTRODUCTION

Empowering patients to manage their diabetes is an important, effective strategy to improve diabetes health outcomes [1, 2]. Yet, doing so in real-world settings remains a challenge, particularly for racial/ethnic minority populations and those from lower socioeconomic backgrounds (e.g., low-income African-Americans), who suffer disproportionately from diabetes-related morbidity and mortality [3–5] and for whom the reduction of health disparities has become a national priority [6, 7].

Much diabetes translational research has involved patient education with the goal of empowering patients to actively manage their disease in areas such as healthy eating, physical activity, self glucose monitoring, and routine foot care. Educational interventions can improve patient knowledge, self-management

Implications

Research: Culturally -tailored diabetes empowerment programs can improve self-efficacy, behaviors, and clinical outcomes among African-Americans. However, more work is needed to identify effective strategies to enhance shared decision-making among this population. Our findings may have relevance for other racial/ethnic minorities and vulnerable populations with diabetes health disparities, and this research should be extended to other populations (e.g., Hispanics) to assess its feasibility and potential effectiveness.

Practice: African-Americans patients with diabetes often want to be more active in their diabetes care, both in self-care activities and in shared decision-making (SDM). While dynamic classroom instruction may be sufficient to change self-care behaviors, patients may likely need encouragement and support from their health care providers in order to enhance SDM within clinical encounters.

Policy: Sustaining behavioral change and ultimately reducing diabetes disparities among African-Americans will require a comprehensive approach that links empowered patients to motivated health care providers, integrated health systems, and community resources.

skills, and clinical outcomes (e.g., diabetes control) [1, 2], yet the effectiveness of such interventions among minorities and the poor is suboptimal. In addition to well-known barriers to program effectiveness (e.g., limited health literacy, financial barriers, competing priorities, and limited access to fresh fruits/vegetables and safe recreational areas) [8–11], there is a growing recognition that the lack of cultural tailoring may significantly reduce the uptake and/or effectiveness of such interventions [3]. In particular, there is a paucity of interventions that address issues of health care mistrust, perceived bias/discrimination, and other race-related issues that have been identified as barriers to health care utilization among African-Americans [12]. A key recommendation in diabetes translational research has been the incorporation of patient perspectives

and adapting interventions to the resources, culture, and needs of the population [13]. Yet relatively few interventions are tailored for low-income groups, racial/ethnic minorities, and other vulnerable populations [3, 14].

One important area of patient empowerment that is often overlooked in diabetes translational research, and which may disproportionately affect racial/ethnic minorities, is shared decision-making (SDM) wherein patients are equal partners with their physicians in the discussions and decisions about diabetes treatment and clinical care [15–17]. Thus, patient empowerment in diabetes management involves both active self-management at home and SDM within the clinical setting [18, 19]. When patients and physicians set diabetes self-care agendas together, patients are more able to make the lifestyle changes needed to manage their condition [20]. Shared decision-making is associated with better control of diabetes and hypertension, higher ratings of self-reported health, and shorter hospitalizations [21, 22].

Despite evidence that African-Americans want to participate in shared decision-making as much as their white counterparts [23], multiple studies have documented that physicians engage African-American patients less in the SDM process than white patients [24, 25]. We previously reported several key patient-identified barriers to shared decision-making among African-Americans with diabetes, including patient-related factors (e.g., familial experiences, self-efficacy), physician-related barriers (e.g., interpersonal skills, accessibility, and availability), and the patient/provider power imbalance that was perceived to be exacerbated by race and class [26, 27]. Race was a particularly salient theme, and African-Americans in our studies identified physician bias/discrimination and/or cultural discordance as issues that may influence physician-related SDM behaviors (e.g., less likely to share information (test results)) with African-American patients [26, 27]. They identified mistrust of white physicians, negative attitudes, and internalized racism as patient-related issues that may influence African-Americans' SDM behaviors (e.g., less forthcoming with physicians about health information, less likely to adhere to treatment) [27].

Thus, race-related patient and physician-related barriers may serve as significant barriers to shared decision-making between African-American patients and their physicians. Finding innovative ways to address such communication barriers is an important area of translational research. Only one study has examined the efficacy of an SDM intervention among African-Americans and it had no effect (although it increased patient communication among whites); a finding the authors attribute to the intervention's lack of cultural appropriateness [28].

There is a need and a growing call for tailored, culturally competent educational interventions that empower African-American patients to self-manage their chronic disease and become more participatory

in their health care decisions [17, 29, 30]. This may be particularly true for patients with diabetes where shared decision-making during primary care encounters has been shown to subsequently improve patient activation, self-care behaviors (i.e., medication adherence), and ultimately, clinical measures (e.g., HbA1c and LDL cholesterol) [31]. To date, however, there have been no diabetes translational interventions that simultaneously address these two areas of diabetes empowerment (self-care and SDM) among African-Americans, yet both are critical and interdependent. Patients need information and self-care skills about their diabetes to feel confident participating in decisions about their health care with their physician; plans for diabetes treatment and self-care that are paternalistically decided by physicians (i.e., without shared decision-making) are more likely to have suboptimal patient adherence.

We developed and pilot-tested a patient empowerment intervention to meet the cultural and socioeconomic needs of low-income African-American patients with diabetes. Our intervention did not merely *target* African-Americans with diabetes for participation; it *tailored* the curriculum for this population's needs. Our efforts to develop the patient activation curriculum was informed by our prior research with African-Americans with diabetes (particularly those living on the South Side of Chicago) that identified barriers/facilitators to shared decision-making, current literature about culturally tailoring interventions, and the team's prior experience tailoring interventions for African-Americans [12, 26, 27]. The intervention combines culturally tailored, evidence-based diabetes education with skills training in communication and shared decision-making.

While self-care and SDM are both important aspects of patient empowerment, it is important to note that they are not the only aspects. We chose self-care and SDM because of: (1) the substantial data linking diabetes self-care and shared decision-making to positive diabetes outcomes; (2) the fact that African-Americans are disproportionately less involved in these two areas than whites (which may be an important contributor to diabetes health disparities); and (3) we are unaware of prior interventions that combine these two aspects of empowerment and tailor them for African-Americans.

Our primary goal was to test the feasibility of implementing this program among a sample of African-Americans with diabetes. We hypothesized that the intervention would be feasible and have high patient satisfaction scores. A secondary goal was to explore potential program effectiveness as measured by diabetes self-efficacy, self-care behaviors, and clinical outcomes (e.g., HbA1c, body mass index (BMI)), although the small sample size limited the power to detect small changes.

The behavioral intervention piloted in this study is part of a multi-targeted intervention to improve

diabetes care and outcomes on the South Side of Chicago, a predominantly working class African-American community with substantial racial disparities in community resources (e.g., food deserts, safe recreation) and diabetes outcomes [32]. And our work in Chicago is part of the national effort on behalf of the Alliance to Reduce Disparities in Diabetes to improve outcomes in our country's most vulnerable populations [33]. For example, nearly all of the food deserts in Chicago are in predominantly African-American neighborhoods, and, in 2003, the diabetes death rate was nearly twice as high in communities with the worst "food balance" scores (the distance to any grocer divided by the distance to any fast food venue) in comparison to those with the best scores [34]. Our intervention, "Improving Diabetes Care and Outcomes on the South Side of Chicago" is a collaboration among the University of Chicago, community health centers, and community partners and consists of four key components: patient empowerment, health provider training (e.g., communication skills, continuing education), health systems change (through the use of quality improvement teams), and community partnerships [33].

METHODS

Study design, setting, and participants

This observational cohort pilot study took place in a federally qualified health center (FQHC) that is part of a large FQHC network in Chicago, IL. After receiving approval from the University of Chicago Institutional Review Board, a letter was sent to individual physicians at the health center explaining the study's general principles. Eligible patients include African-American adult patients (ages 18 years and older) with diabetes who received care at the FQHC. Patients were referred from primary care physicians, subspecialists, and diabetes educators. Potential participants were contacted via telephone by two staff members (a dietician and nurse) from the FQHC using a standardized protocol to recruit patients, and verbal consent was obtained. These staff members were members of both the research team (e.g., helped develop the curriculum) and the intervention team (e.g., taught/facilitated the class). Written consent was obtained immediately prior to the first class. Incentives for study participation included a glucometer and initial supplies (test strips, lancets), \$20/survey for each round of survey completion, and entry into a raffle for one of two \$100 gift certificates to a local grocery store for those who completed at least 70% of the classes. Bus passes were provided as needed to address a common transportation barrier to program participation among the urban poor. Two cohorts of participants were included in the pilot study; recruitment occurred in the 2 months preceding the first class—February–March 2010 (cohort 1) and June–July 2010 (cohort 2). We recruited 25 participants

for the intervention. Four people were unable to participate from cohort 1 (two had family emergencies, one became acutely ill, and one had schedule conflicts with work) and all recruited patients in cohort 2 participated in the program. Thus, there were 21 participants in the pilot study, 11 patients in cohort 1 and 10 patients in cohort 2. Data were collected at baseline, at the end of the 10-week intervention, at 3-month follow-up from the end of the intervention, and at 6-month follow-up. Follow-up data were collected at the FQHC to coincide with quarterly cohort meetings of the "Diabetes Club" (the peer support group into which class participants transitioned at the end of the 10-week intervention to allow for ongoing peer support and group-led learning). Reminder phone calls were made to minimize loss to follow-up, and data collection dates were rescheduled within 1–2 weeks for participants who missed follow-up sessions. The intervention was taught by a registered nurse/certified diabetes educator (CDE), a registered dietician, and a primary care physician.

Curricular development

The patient empowerment intervention was developed using evidence-based, culturally tailored, theoretically driven models of diabetes education and patient empowerment through a multidisciplinary team of nurses, diabetes educators, a social psychologist, physicians, researchers, dietitians, patients, and clinical staff. After several meetings to discuss the goals, format, and general content of the intervention, a smaller working group consisting of a nurse, dietician, diabetes educator, and a physician developed the curriculum and modified it several times based on feedback from the larger team. The ten-session program consisted of weekly classes that were modified iteratively in real time. The first six sessions consisted of general diabetes education, the next three sessions focused on shared decision-making and patient/provider communication, and the last session provided a review of curricular materials and additional opportunities to practice self-care and SDM skills. At the end of each class, the participants were asked about content and logistical areas that were particularly effective or needed improvement. In addition, a longer debriefing was held at the end of the 10-week sessions where we elicited additional feedback from participants about strengths and weaknesses of the program.

Diabetes education

The diabetes education sessions were co-taught by the RN/CDE and the RD, both of whom had extensive experience working with African-American patients with diabetes. Light snacks were provided at

the sessions as an incentive and to model appropriate food choices.

The BASICS diabetes curriculum was created by the International Diabetes Center with the goals of improving disease knowledge and self-management skills [31]. BASICS is grounded in the frameworks of the health belief model and the transtheoretical model (stages of change) [35, 36]. In the health belief model, patient behavior depends upon both the desire to avoid illness (e.g., diabetes complications) and the belief that specific actions (e.g., physical activity, medication adherence) will prevent or ameliorate illness. According to the transtheoretical model, people exist along a continuum of motivational readiness to change a problem behavior (e.g., poor dietary habits); these “stages of change” are effected by “processes of change” such as consciousness raising (i.e., increased awareness of the causes, consequences, and cures of a problem behavior). The BASICS curriculum covers the following key areas: diabetes basics (e.g., basic physiology, treatment, complications, and comorbid conditions), nutrition, physical activity, and diabetes self-management (e.g., glucose monitoring, goal setting, symptoms and management of hypoglycemia and hyperglycemia, and problem solving). The standard BASICS curriculum is delivered in four sessions of 2 h each over a 9-month period with progressively longer intervals between sessions.

We revised the BASICS diabetes curriculum to fit the socioeconomic and cultural background of our patient population. We modified logistical aspects of the BASICS program based on principles of health literacy [37] and adult learning theory [38]. For example, we reduced the length of each session and increased the total number of sessions (to reduce the volume of information transmitted per session), reduced the time between sessions (to reinforce previously learned material), and used repetition through regular review of key concepts. The revised schedule was delivered in six sessions of 80 to 90 min with classes held on a weekly basis. We also

incorporated the use of audiovisual aids (to address potential literacy barriers to written materials) and incorporated the use of interactive role-play to reinforce more complex concepts (e.g., how insulin acts to regulate blood glucose levels). We also culturally tailored the curriculum. For example, drawing upon the oral tradition of storytelling and the religious tradition of “testifying” in the African-American community, we encouraged patients to share stories about their challenges and successes with managing their diabetes [39] and used a group format to discuss goal setting each week. Because of the particularly important role of family among African-Americans in health care decision-making and social support [40], participants were also encouraged to bring a family member or friend to the sessions to reinforce lifestyle modifications within the home and social environment. We also sought to create a socially cohesive, familial environment within the class, where honest dialogue about the psychosocial challenges of diabetes was welcomed and facilitated.

We also culturally tailored the lifestyle instruction, such as the nutrition education that addressed the shopping and dietary patterns common to our patients. Most African-Americans in Chicago were part of, or descendants of, the “Great Migration” of blacks from the South [41]. The food practices of many Southern African-Americans originate with slavery when slave owners gave lard and discarded animal parts (e.g., pigs’ feet and intestines) to slaves as staple items in their food rations [42]. These foods and their preparation have become cultural traditions within the community [42]. The team created a mock grocery store based on the labels and packaging of food items available in locally utilized grocery stores which were donated by class participants (Fig. 1). Class members would “shop” at the grocery store to practice various nutritional skills (e.g., reading food labels, carbohydrate counting). Personal recipes for diabetes-friendly foods (e.g., peach cobbler that utilized sugar substitutes and other healthy

Fig. 1 | Mock grocery store within diabetes educational classroom

substitute ingredients) were shared by class participants and others were provided by the dietitian based on dietary patterns documented in the weekly food logs participants provided. Thus, the class started from existing dietary patterns and modified them to create healthier food purchasing and preparation habits. These alternatives aligned with participants' cultural traditions, providing a sustainable method of dietary adherence.

Recommendations for physical activity were also tailored to our patient population, who were primarily middle-aged adults with physical limitations (e.g., osteoarthritis, peripheral vascular disease) and limited access to safe recreation outside of their homes. For example, we utilized jazz music and elastic bands to demonstrate how one could use existing and low-cost resources to meet current recommendations of the American Diabetes Association (ADA) for physical activity. Finally, we identified, along with class participants, existing community resources to help participants manage their diabetes and overcome logistical (e.g., cost, distance) barriers to self-care.

Shared decision-making

The SDM intervention was created by a team of physicians, patients, nurses, a social psychologist, education specialists, diabetes educators, and researchers. It built upon our prior work to understand shared decision-making among African-Americans with diabetes, particularly as related to race, cultural discordance, and perceived bias/discrimination [12, 23, 26, 27, 43]. It also utilizes the framework of the patient empowerment model [18]. The curriculum addresses perceived barriers, behavioral beliefs, and subjective norms around SDM as well as communication and negotiation skills.

Patients were taught to: (1) ask more questions (*information seeking*), particularly about the risks/benefits of tests/treatments; (2) give more detailed information (*information provision*), especially about lifestyle issues, preferences for quality vs. quantity of life, etc.; (3) clarify/restate what the doctor says (*information verifying*) to ensure full patient understanding; and (4) share in the decision-making process by explicitly stating preferences for tests and treatments that reflect lifestyle choices. Prior interventions have focused on patient communication skills within the medical domain (i.e., symptom reporting) [44]. This intervention is novel in that it facilitates discussion about lifestyle issues that impacts ownership of and adherence with the plan of care.

These skills were taught within the framework of the three central domains of shared decision-making, as defined by Charles et al.: information sharing, deliberation, and decision-making [15, 16]. We translated these concepts into simple, accessible terms: discuss, debate, and decide. In addition, the

ADA standards of clinical care [45] were taught in the class as a means of educating patients about appropriate expectations for care delivery and utilized as a framework for discussing patient/provider communication and shared decision-making about clinical care and treatment decisions.

The SDM education component used an interactive format with problem-based learning, group discussions, role-play, individual testimonies, and experiential learning. Patients were asked to keep journals to help elucidate lifestyle priorities and preferences that were meaningful to clinical decision-making. Participants ended each session by setting a behavioral goal for the next week; goals were first introduced by the class facilitator, then individuals were given time to reflect and select personal goals, and finally, goals were discussed within the group.

Behavioral goals were set for each of the key domains in the BASICS curriculum (e.g., physical activity, problem solving) and in shared decision-making (e.g., information sharing). Experiences (challenges/successes) with these behavioral efforts were reviewed at the beginning of each new session.

We developed and utilized several audiovisual tools to support the curriculum, such as an interactive game entitled "Who wants to have a say in their healthcare?" (modeled after the television show "Who wants to be a millionaire?") whose categories include BASICS [diabetes education], discuss, debate, and decide (Fig. 2). This game addresses many of the barriers and facilitators to SDM identified in our qualitative research, thus allowing patients to discuss these issues in a group setting without specific individuals having to admit to beliefs, attitudes, or behaviors that may hinder SDM (e.g., the use of treatment non-adherence rather than dialogue as a means of expressing disagreement with a physician's recommendation) [26, 27]. We also created an educational video that uses two case stories of African-American patients to demonstrate what "good" and "bad" examples of patient/provider communication and SDM may look like in the clinical setting [46]. This allowed patients to translate abstract concepts into tangible behaviors and skills that could be learned and reinforced during the class. The video also discusses several culture-specific barriers to SDM that exist within the African-American community (e.g., heightened physician deference that stems from historical structural inequality) [26, 27].

Although the SDM classes took place during three sessions following the modified BASICS curriculum, key elements of SDM were introduced early in the BASICS class and interspersed throughout to help integrate the two concepts. For example, the educational video was shown during the first class and references to it were utilized throughout the six BASICS classes. In addition, although the SDM curriculum focuses on communication techniques, it drew upon and reinforced material from the BASICS

DEBATE

Fig. 2 | Example game card of the “Who wants to have a say in their healthcare?” interactive game

curriculum. Thus, we sought to create an integrated experience of patient empowerment that built upon both diabetes education/self-management and shared decision-making lessons simultaneously. For example, during the SDM curriculum, patients would role-play telling their doctor about their treatment goals for diabetes management (which they identified during the BASICS curriculum). The video contextualizes patients in their home environments and shows how challenges in diabetes self-care (e.g., new challenges with medication adherence that arise from a new job) can be addressed with the use of shared decision-making with the physician. In addition, the didactic sessions about the importance of providing information to your doctor gave examples based on diabetes experiences (i.e., symptoms of hyper/hypoglycemia, medication side effects, etc.) that patients learned about and discussed in class.

The Diabetes Club

After program completion, each cohort was transitioned into a diabetes support group (“The Diabetes Club”) that met quarterly for patient-led learning (through the use of US Diabetes Conversation maps® [47]), peer support, and moderated discussions about self-care and shared decision-making challenges and gains. The Diabetes Club meetings provided reinforced education and skills and peer support, with the goal of enhancing overall study retention and sustained behavioral changes. Three-month and 6-month follow-up data collection

occurred immediately prior to the quarterly Diabetes Club meetings.

Survey measures and instruments

Diabetes self-efficacy—Diabetes self-efficacy was measured with a four-item instrument (with five-point Likert scale responses ranging from “strongly agree” to “strongly disagree”) that assesses confidence and ability to manage one’s diabetes. The DSE correlates with glycemic control and clinical outcomes [48]. Composite scores were converted to a 0–100 scale and treated as a continuous variable.

Diabetes self-care measures—The Toobert et al. Summary of Diabetes Self-Care Activities Measure assesses five areas of self-care practices over the past 7 days (with response options ranging from 0 to 7): diet, exercise, blood sugar testing, foot care, and smoking. It is a brief, valid, and reliable measure of self-reported self-management that correlates with other measures of dietary patterns (e.g., 3- and 4-day food records) and physical activity (e.g., enrollment in an exercise class) [49]. Mean scores for each subscale are used and were treated as continuous variables.

Shared decision-making self-efficacy—Patient self-efficacy in shared decision-making was measured by the decision self-efficacy scale, an 11-item instrument (with three-point Likert scale responses ranging from “not confident” to “a lot confident”) which measures self-confidence in decision-making, including shared decision-making [50]. It is a validated

scale with good internal consistency (0.78–0.84); it has been used in a range of patient populations, including middle-aged adults with chronic disease [51]. Scores were converted to a 0–100 scale and were treated as continuous variables in the analyses.

Shared decision-making behavioral measures—Patient and provider shared decision-making behaviors were assessed through the perception of involvement in care scale (PICS), a self-reported patient questionnaire divided into three subscales that measure doctor facilitation of SDM, patient information sharing, and patient decision-making [52], each of which represents key concepts in SDM [15, 16]. The PICS has good reliability (Cronbach's alpha, 0.73) and validity, and it is associated with patient satisfaction, patient understanding, perceived control, and expected improvement in functional capacity [52]. Responses are close-coded in a binary agree/disagree format (0/1). Mean scores for each subscale were calculated and treated as continuous variables in the analyses.

Clinical outcomes—We measured the following clinical variables: HbA1c, systolic blood pressure, diastolic blood pressure, cholesterol (LDL and HDL), weight, and BMI. LDL and HDL were measured in cohort 2 only. HbA1c, LDL, and HDL were measured via venipuncture samples taken immediately prior to survey administration by medical assistants in the clinic (for cohort 1, HbA1c values were not obtained at one of the time points (program's end) due to medical staff unavailability). Blood pressure, weight, and height were also measured prior to survey administration and were measured by nursing staff at the clinic.

Patient satisfaction and program evaluation—As part of the post-intervention survey, participants were asked four closed-coded program evaluation questions (utilizing a five-point Likert scale) about overall program satisfaction, whether they would recommend the class to friends/family, whether they felt they learned a lot about self-management, and whether they felt they learned a lot about shared decision-making. These were followed with open-ended questions about program strengths and weaknesses. Although general themes were identified, these data were not subjected to formal qualitative analyses.

Data analysis

We conducted descriptive analyses of the patient sociodemographic and clinical characteristics, and the program evaluation, and patient satisfaction data. The open-ended program evaluation questions were qualitatively assessed; three team members reviewed the data and abstracted themes.

Patient survey data were collected at baseline, program completion, and 3 and 6 months to assess diabetes self-efficacy, self-care behaviors, and communication measures. All time points were compared to baseline values (e.g., T1 vs. T2, T1 vs. T3,

etc.), since we were primarily interested in the sustainable effects of the initial intervention (versus potential changes in behaviors over time). Because of the small sample size and skewed nature of the data, we used Wilcoxon sign-rank tests. STATA 10.0 was used for all analyses. We defined statistical significance as a p value of <0.05 .

RESULTS

Patient characteristics

The mean age of participants was 66 years, and 88% were women (Table 1). Less than half (44 %) had completed high school and 62% had an annual household income of less than \$15,000. The vast

Table 1 | Patient characteristics ($n=21$)

	Percent
Age (mean)	66 years
18–39	24
40–54	38
55–64	33
65–74	5
Female gender	88
Marital status	
Single	38
Married/living as married	14
Separated/divorced/widowed	48
Education	
Some high school or less	56
High school graduate	24
Some college	10
College graduate or higher	10
Income, \$	
<15,000	62
15,000–24,999	38
Living Space	
Rent	90
Own	10
Insurance	
Uninsured	5
Medicare	48
Medicaid	33
Private insurance	14
Mean duration of diabetes, years	7.7
Medication regimen	
Lifestyle modification only	5
Oral agents w/o insulin	68
Insulin	11
Oral agents w/ insulin	16
Diabetes complications	
0	33
1	53
2	14
Comorbid illnesses	
Cerebrovascular disease	10
Coronary artery disease	24
Hypertension	95
Hyperlipidemia	43
Peripheral vascular disease	38

majority of patients (95 %) had some form of health insurance, most commonly Medicaid or Medicare (no patients were dually eligible). The mean duration of diabetes was 7.7 years, and approximately half of the participants (53 %) had at least one diabetes complication. Nearly all patients (95 %) had hypertension, and all had some form of atherosclerosis (e.g., coronary artery disease, peripheral vascular disease) or hyperlipidemia.

Patient satisfaction and program evaluation

All participants attended at least 50% of the classes. Eighty-six percent attended 70% or more of the classes, and 38% attended each of the ten sessions. All 21 participants “strongly agreed” that they were satisfied with the education and communication aspects of the intervention, would recommend the class to friends/family, learned a lot about self-management, and felt they learned a lot about shared decision-making.

In the open-ended questions about the curriculum and program evaluation, participants were uniformly positive. They liked the educational information about diabetes, the self-care skills building activities (e.g., carbohydrate counting, reading food labels), and the communication skills. One participant wrote “I’ve learned more in this one class than I’ve ever known about my diabetes!” Participants liked the hands-on approach and interactive format: “The role playing was the most helpful part” and “Some things that I thought I knew, they cleared it up by giving lots of examples.” Participants described feeling empowered to talk to their physician and be more active in decision-making about treatment options. One person noted “it was like you were at a real doctor’s visit... I felt more courageous and not

nervous as usual.” Another wrote “I learned how to be open with my doctor.” Participants also appreciated that the class was grounded in real experiences and cultural traditions that they could identify with. One participant stated “(Class instructor) is not just talking about diabetes from a book, but from real life experiences. That was helpful.” The one noted area for improvement was physical activity; a few participants wanted more time and space devoted to physical activity. Unfortunately, the meeting room was not large enough to support only simple exercise activities.

Diabetes self-efficacy and self-care

There were improvements in the composite measure of diabetes self-efficacy that were noted at the program’s end (69.8 vs. 86.4, $p=0.005$) and at 3-months (69.8 vs. 87.9, $p=0.003$). At 6 months, sustained improvements were noted but the difference was no longer statistically significant (69.8 vs. 80.4, $p=0.57$).

Patients’ self-reports of diabetes self-management improved in each of the five areas: following a healthful eating plan (over the past week and over the past month), self glucose monitoring (amount of testing over the prior week and testing the amount recommended by one’s health care provider), foot care (checking feet and inspecting the inside of one’s shoes), and smoking (smoking status and number of cigarettes per day) (Table 2). Following a healthful eating plan, self glucose monitoring and self foot care met statistical significance. As with self-efficacy, improvements were generally sustained at 3 months and began to wane at 6 months. For example, the mean number of days that participants followed a healthful eating plan in a week increased from 3.4 at

Table 2 | Self-reported diabetes self-efficacy and self-management behaviors ($n=21$)

	Baseline	Program end	p value	3-month follow-up	p value	6-month follow-up	p value
Diabetes self-efficacy ^a (mean [sd])	69.8 (17.9)	86.4 (16)	0.005	87.9 (13)	0.003	80.4 (15.5)	0.57
Diabetes self-management behaviors ^b (mean [sd])							
	($n=20$)	($n=17$)		($n=17$)		($n=14$)	
“Healthful eating plan”	3.4 (2.3)	5.2 (2.3)	0.002	5.3 (1.7)	0.04	4.3 (2.1)	0.13
High fruits/vegetables and low fat intake	4.3 (1.8)	4.9 (1.6)	0.28	4.7 (1.3)	0.76	4.7 (1.5)	0.78
Exercise	3.2 (2.2)	3.2 (2.3)	0.09	3.4 (2.8)	0.25	3.8 (2.7)	0.004
Self glucose monitoring	4.2 (3.0)	6.2 (1.5)	0.04	5.3 (2.4)	0.34	5.5 (2.2)	0.84
Self foot care	4.4 (2.4)	6.0 (1.9)	0.001	5.9 (2.0)	0.04	6.1 (1.5)	0.01
Smoking	6.4 (17)	0.93 (2.0)	0.48	3.9 (4.7)	0.17	3.3 (2.1)	0.29

p values represent comparisons between baseline values and subsequent time points. p values are based on Wilcoxon signed-rank tests

^a Based on a four-item instrument with five-point Likert scale response items ranging from “strongly agree” to “strongly disagree.” Scores were converted to a 0–100 scale

^b Based on the Summary of Diabetes Self-Care Activities Measure (SDSCA) instrument, which assesses five areas of self-care practices over the past 7 days (with response options ranging from 0 to 7): following a “healthful eating plan” (over the past week and over the past month), consuming recommended amounts of fruits/vegetables and low amounts of high-fat foods, exercise (general physical activity and a specific exercise session (e.g., swimming)), self glucose monitoring (amount of testing over the prior week and testing the amount recommended by one’s healthcare provider), foot care (checking feet and inspecting the inside of one’s shoes), and smoking (smoking status and number of cigarettes per day). Mean scores for each subscale are reported

baseline to 5.2 at the end of the intervention ($p=0.002$), was 5.3 at 3 months ($p=0.04$), but decreased to 4.3 at 6 months ($p=0.13$). However, foot care had sustained improvements throughout, and there were slow, but steady, improvements in physical activity over time, with a peak at 6-month follow-up that met statistical significance (2.9 at baseline vs. 3.8 at 6 months, $p=0.004$).

Shared decision-making self-efficacy and behaviors

Although decision-making self-efficacy scores improved by the end of the class (mean score of 80.0 at baseline (scale, 0–100) vs. 83.5 at the program's end) and at follow-up (3 months, 88.5; 6 months, 87.0), these changes were not statistically significant (Table 3). Patient SDM behaviors in the areas of information sharing and decision-making were largely unchanged over the measured time periods, as were patient reports of physician facilitation of SDM.

Clinical outcomes

Improvements occurred in HbA1c values and systolic blood pressure values, although only the 3-month HbA1c value met statistical significance (8.24 at baseline vs. 7.33, $p=0.02$) (Table 4). No changes were noted in diastolic blood pressure or weight/body mass index. Improved LDL and HDL measures (collected only in cohort 2) were noted but were only statistically significant for HDL at 6-month follow-up (51.2 at baseline vs. 61.8 at 6-month follow-up, $p=0.01$).

DISCUSSION

We developed a patient-centered, culturally tailored approach to empowering low-income African-American diabetes patients to improve self-care and increase shared decision-making. Our intervention proved feasible, received high patient satisfaction ratings, improved diabetes self-efficacy and self-care behaviors, and improved HbA1c at 3 months and HDL cholesterol at 6 months. We did not,

however, note significant improvements in SDM self-efficacy or behaviors.

The primary goal of the pilot was to iteratively modify the curriculum and assess the overall feasibility of the intervention. Yet, despite the small sample size, we were able to demonstrate improvements in several key outcomes. Diabetes self-efficacy and self-management behaviors were notably improved. Patients felt more confident in their ability to do their own routine diabetes care and manage their condition. And despite the socioeconomic challenges and environmental barriers to lifestyle modification, they were able to improve their dietary patterns, particularly in the general area of following a healthful eating plan. Improvements in physical activity gradually increased over time and actually peaked at the 6-month follow-up period. We also saw improvements in self glucose monitoring and self foot care. These findings are particularly noteworthy given current literature suggesting that it takes 3 months to develop new behaviors [53]. We found statistically significant behavioral changes at the end of the 10-week program. Our findings suggest that that our patients may have been particularly motivated to engage in behavioral changes, a theory which is corroborated by the statistically significant improvements in HbA1c values at 3 months and HDL cholesterol at 6 months. The alternative explanation is that our patients were not accurately reporting their self-care behaviors. However, the Toobert instrument we used to measure self-care has been previously validated and corresponds to other behavioral measures of nutritional habits [e.g., 3- and 4-day food records, exercise self-monitoring data, and attendance at an exercise class] [49].

Qualitatively, patients reported feeling more empowered to engage in shared decision-making, and SDM self-efficacy scores improved, although they were not statistically significant. These nonsignificant changes may have been due to one of two reasons: (1) the intervention worked but was underpowered due to the small sample size; (2) the

Table 3 | Self-reported shared decision-making self-efficacy, patient behaviors and physician behaviors ($n=21$) (mean, [sd])

Communication measures	Baseline	Program end	p value	3-month follow-up	p value	6-month follow-up	p value
Patient SDM self-efficacy ^a	86.0 (11.9)	83.5 (10.3)	0.78	88.5 (12)	0.90	87.0 (11.7)	0.60
Patient information sharing ^b	3.1 (1.2)	2.5 (1.6)	0.36	3.0 (1.4)	0.84	3.3 (1.2)	0.71
Patient decision-making ^b	1.5 (1.5)	1.6 (1.4)	0.35	1.9 (1.9)	0.37	1.1 (1.3)	0.33
Physician facilitation ^b	3.9 (1.6)	3.4 (1.8)	0.54	2.8 (2.1)	0.14	3.6 (1.6)	0.93

p values represent comparisons between baseline values and subsequent time points. Mean scores are presented. p values are based on Wilcoxon signed-rank tests

^a Based on the decision self-efficacy scale, an 11-item instrument with three-point Likert scale response items ranging from “not confident” to “a lot confident.” Scores were converted to a 0–100 scale

^b Based on subscales of the perception of involvement in care scale (PICS). Response items are close-coded in a binary agree/disagree format. Ranges for the PICS subscales are as follows: patient information sharing (0–4), patient decision-making (0–4), and physician facilitation (0–5)

Table 4 | Clinical outcome measures ($n=21$) (mean [sd])

Clinical measure	Baseline ($n=20$)	Program end ($n=17$)	p value	3-month follow-up ($n=17$)	p value	6-month follow-up ($n=14$)	p value
HbA1c (%) ^a	8.4 (2.4)	8.3 (1.9)	0.18	7.33 (1.7)	0.02	7.51 (2.0)	0.94
Systolic BP	141 (23.4)	136.9 (20)	0.24	136.8 (18.7)	0.76	126.5 (7.6)	0.43
Diastolic BP	85 (16.2)	79.2 (12.9)	0.23	80.7 (10.6)	0.67	79.5 (8.8)	0.84
Weight (lbs)	236 (54.9)	225.2 (43.3)	0.78	229.6 (62.4)	0.29	227.9 (57.6)	0.57
BMI (kg/m^2)	39.1 (9.7)	38.4 (9.2)	0.64	38.7 (11.7)	0.06	38.6 (10.6)	0.68
HDL (mg/dl) ^b	51.2 (13.3)	68.2 (8.9)	0.25	59.3 (18)	0.08	61.8 (15)	0.01
LDL (mg/dl) ^b	110.3 (36.9)	131.7 (44.2)	0.25	112.3 (33.3)	0.83	103.3 (27)	0.76

p values represent comparisons between baseline values and follow-up time points. Mean scores are presented. p values are based on Wilcoxon signed-rank test analysis

^a Glycosylated hemoglobin values were not obtained at program's end for cohort 1 thus, mean and p value obtained at programs end are specific to cohort ($n=8$)

^b Lipid values represent cohort 2 only. The sample size for each time point is as follows: baseline ($n=10$), program end ($n=6$), 3-month follow-up ($n=9$), and 6-month follow-up ($n=12$)

intervention did not have an impact on measured outcomes. Participants did not, however, report improvements in the SDM behaviors of themselves or their physicians, underscoring how challenging it is to overcome the psychosocial barriers to shared decision-making. Finally, we noted improvements in HbA1c, cholesterol (LDL and HDL), and systolic blood pressure measurements, although the findings were only statistically significant for HbA1c at the 3-month follow-up time period and HDL cholesterol at the 6-month follow-up time period.

Our pilot intervention proved feasible and was well received by patients. The majority of patients attended over 70 % of the ten sessions, and all participants felt strongly that the program was helpful and would recommend it to their friends and/or family. In fact, many participants spontaneously made such recommendations before the classes ended, and we currently have a waiting list of patients eager to join future empowerment classes. Although not formally assessed, anecdotally we heard that the social cohesion and support within the groups was a primary factor in motivating participant attendance and overall satisfaction. We introduced each cohort (including the educational team leaders) as “your new family” and reinforced that concept throughout each session. Although social and familial support is important in disease management and health care decision-making for many people, research suggests it may be particularly important for African-Americans [38]. Social support is thought to facilitate self-care and adaptation to illness, and research among African-Americans has found significant associations between social support and improved diabetes management [54, 55]. Thus, we sought to leverage social cohesion and support within the class to optimize participation, content uptake, and sustainability.

To our knowledge, this is the first culturally tailored diabetes intervention for low-income African-Americans that utilizes a strategy of enhanced self-care and shared decision-making. We translated an evidence-based diabetes curriculum to address

the literacy, socioeconomic and cultural needs, and traditions of low-income African-Americans and combined it with communications skills building in the area of shared decision-making that specifically addressed the racial/cultural and psychosocial barriers to SDM previously identified in our research.

Our methods were grounded in patient experiences: qualitative research with patients laid the framework for the intervention, diabetes patients participated as key members of the program development team, and curricular modifications responded in real time to class participants' feedback about their needs and expectations.

Translating best practices regarding diabetes education and empowerment remains a challenge, yet the potential benefits are significant. This is particularly true for racial/ethnic minorities and low-income populations who suffer disproportionately from the effects of diabetes and often have fewer resources to combat their disease. We found that the behavioral effects of the intervention, though apparently sustained at the 3-month follow-up time period, began to wane at 6 months. This potentially suggests the need for enhanced “booster sessions” of the intervention, either in frequency, intensity, or both. Each of the cohorts transitioned from weekly classes to a Diabetes Club support group/learning session that meets quarterly. The follow-up survey data were collected *prior to* the Diabetes Club meetings, and it is possible that higher scores would have been observed if the surveys were administered afterwards [56].

However, the diminishing effect for several measures, particularly dietary patterns, over time also underscores the powerful role of life circumstances and social determinants in shaping patient behaviors and highlights that a major challenge in translational research is that improving the health of communities must involve transforming communities and not just a few individuals within those communities. The recent strategic planning report of the Diabetes Mellitus Interagency Coordinating Committee notes that behavioral interventions can have “a more

profound impact” if combined with substantive changes with the health care delivery system [17]. The behavioral intervention piloted in this study is part of an ambitious multi-year, multi-site intervention that includes health care provider communication training, health system change and community partnerships [57]. As the overall intervention becomes fully implemented, we anticipate observing greater improvements in each area (e.g., patient empowerment) [3, 58].

One of the key lessons learned from this pilot intervention was that, despite the intense effort at tailoring the curriculum and seeing early evidence of meaningful behavioral change, sustainability of behavioral change was limited. We have begun to integrate subsequent classes more effectively with the community linkages aspects of the intervention, particularly those that involve food, as dietary patterns were the most challenging to sustain in our study sample. For example, we now partner with a local food pantry to provide health screening and information; participants from our diabetes classes are encouraged (and do) attend the monthly pantries where fresh produce and other healthy foods are given to local residents. During the food pantry events, we provide cooking demonstrations with food items distributed that day and pass out recipes for the dishes prepared. Our team is also collaborating with a local farmer’s market and national retail store to provide free food “prescriptions” for healthy foods and working with the city’s park district to disseminate prescriptions for free access to exercise facilities for persons with diabetes. We anticipate that we will have more success sustaining behavioral change in our motivated and activated patients when they have additional community resources that support their efforts.

Another key lesson learned was that enhancing shared decision-making in this population may be a particularly challenging task. We saw modest, non-significant, improvements in SDM self-efficacy and no change in SDM behaviors. Thus, it is unlikely that SDM impacted the improvements in HbA1c (noted at 3 months) or HDL cholesterol (noted at 6 months). Feedback from class participants suggested that provider barriers were an important issue. We have subsequently reorganized the provider communication workshops (e.g., to include specific details about SDM barriers/facilitators among African-Americans with diabetes) and changed the timing to precede or coincide with the implementation of the patient activation classes.

We noted a 0.91% absolute reduction in HbA1c at 3 months, which is comparable to findings from a systematic review of health care interventions to reduce diabetes disparities, where culturally tailored patient interventions improved HbA1c values by 0.69% (in comparison to a 0.10% reduction in non-tailored patient interventions) [3]. Thus, integrating patient empowerment within larger efforts to engage health care providers, change health systems, and

link patients to community resources may be critical to sustaining the efforts of activated patients and to ultimately reducing diabetes disparities on a larger scale.

Lessons learned from this current study will have broad implications for patients, health systems, communities, and policy makers as we strive to improve the health of some of the most vulnerable communities in USA. In addition, there are important research implications from this study. For example, more work is needed to identify effective strategies to enhance shared decision-making among African-Americans with diabetes. Our findings may have relevance for other racial/ethnic minorities and vulnerable populations with diabetes health disparities, and this research should be extended to other populations (e.g., Hispanics) to assess its feasibility and potential effectiveness.

There are several limitations to the study. First, the sample size was small, and as such, we were not sufficiently powered to detect differences in many of the measured outcomes, and our findings may not be generalized to all urban low-income African-Americans, particularly African-American men as they were underrepresented in our sample. However, the goal of the study was primarily to evaluate the feasibility and acceptability of the intervention, not to assess program effectiveness. Second, the “specific diet” subscale of Toobert’s self-care instrument has low internal consistency and may not adequately capture this domain [49]. Third, baseline self-assessments of SDM self-efficacy were fairly high and may have limited our ability to measure changes over time. Patients may have answered baseline survey questions based on preconceived ideas about SDM; their self-assessments may have changed after they learned more about SDM in the class. Alternatively, patients who volunteered to take the classes may have had higher baseline levels of communication self-efficacy than the general population, and thus, may have subsequently biased our results toward a null effect. Finally, this study is not a randomized trial, and selection bias may have affected our results. Motivated patients may have been more willing to participate in the study, which would have biased our results towards positive findings.

Nonetheless, our study has several strengths. We used qualitative and quantitative data, along with evidence-based programs and a theoretical approach, to develop an innovative patient empowerment intervention that addresses diabetes self-care and shared decision-making. In addition, this pilot is embedded in a larger multi-targeted intervention that seeks to leverage health care providers, clinic staff, and community resources to improve patient outcomes. Further advances in diabetes translational research are needed to address health disparities among low-income African-Americans.

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